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ABSTRACT

Questionnaires were completed by 330 parents of developmentally disabled children on such topics as labeling and competency, mainstreaming, anticipated needs for residential care, family integration, diagnosis and assessment, and community resources. These factors were investigated according to demographic variables. Among findings were that children from Black families had more social interactions with a wider variety of people and were evaluated as having better interpersonal skills than were children of White families; family income did not seem to be systematically associated with attitudes toward mainstreaming; females were more likely to be expected to remain at home or to live on their own and to work in a sheltered workshop while males were more likely to be expected to live in a community facility and work in the community; the higher the family income the more likely mothers were to express negative feelings and perceive negative effects; about 90% of the parents were satisfied with their children's school; and the only family activity influenced by income was religious participation. Service needs and satisfactions noted include personal and community support networks and organizational and political involvement. (CL)

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Parents' Choice of Services for Developmentally Disabled Children:

Final Report

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INTRODUCTION

This is the final report of a mail survey questionnaire completed by 330 parents of developmentally disabled children ages 0-21 who were receiving services in Lake County, Illinois. For the purposes of this study, developmentally disabled is defined as children handicapped by mental retardation, cerebral palsy, epilepsy, autism, or multiple handicaps involving one or more of the foregoing, and whose handicap required more than 50 percent time in a special education program. Questionnaires were mailed out over a three-month period from mid-March to mid-June 1978. The report focusses on issues concerning labeling and competency, normalization, family integration, diagnosis and assessment, community resources, and organizational involvement. The report provides breakdowns showing how these issues are affected by the age of the developmentally disabled child, the type of disability, family income, and race. Age, disability, income, and race were selected as explanatory variables because these are attributes which are readily identifiable by professionals and the public.

Optimizing the use of community-based services by developmentally disabled persons is in keeping with the policy of maintaining developmentally disabled persons in community-based "normalizing" environments. This project was designed to provide information regarding the manner in which parents successfully or unsuccessfully secure the community services needed by their developmentally disabled children.

History of the Research Problem and Current Status of Work

As the mediator between the individual and society, the family is the basic social institution. It interprets society's rules of conduct for its members. Yet the term, family, subsumes a wide range of diversity in structure, function, values, and lifestyles. The services that the family provides for its members, other than the affectional, have been transferred to outside agencies with the advent of industrialization and urbanization (Winch, 1971). Of particular importance, responsibility was transferred from home to school for increasing portions of the child's education. The family provides the child with a place in society, with an ascribed social position, to which a developmental set of expectations are attached. The educational system generalizes these expectations by age-grade levels to establish a standardized set of achievement norms which all children are expected to attain in order for their socialization and development to proceed as projected. The developmentally disabled child cannot attain all of the complex cognitive, physical, social, and emotional developmental achievement norms prescribed by the generalized educational system. For the developmentally disabled child, generalized norms must be replaced with ones which are more particularistic and individualistic. The extent of the child's disability, available alternatives, and the parents' emphasis on the importance of the generalized achievement norms will determine the nature of the particularistic and individualistic resolution sought.

The developmental model of our educational institutions assumes behavior can be modified and that all individuals are capable of growth, development, and learning. Special institutions for the developmentally disabled, and others who deviated from the "normal," were founded for the purpose of congregating them in one area so they could receive specialized attention. As Wolfensberger (1975: 24) states, from reading primary sources around the 1850's when many institutions were founded, "the goal was a combination of diminishing the intellectual impairment and increasing adaptive and compensatory skills of pupils so that they would be able to function at least minimally in society." Unfortunately socialization was defined in a limited cognitive fashion and the location of insitutions was determined more by economic and political than by familial needs. The developmentally disabled were aggregated into large omnibus (rather than specialized) institutions, often in rural areas, thereby effectively segregating them from their families and the community. Developmental goals became replaced by custodial ones. It was not until the 1950's, with the advent of prosperity following a depression and two world wars, that significant public concern again began to be expressed with equal protection under the law, including better opportunities for the developmentally disabled.

Deinstitutionalization. The concept of "normalization" was coined in the 1960's to symbolize a new concept of human management and acceptance, as: "Utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behaviors and characteristics, which are as culturally normative as possible" (Wolfensberger, 1972: 28). One mechanism for achieving normalization is that of deinstitutionalization, the removal (partial or complete) from an institutional facility (prison, school for misdemeanants, mental patient's hospitals, etc.) of an individual who has been interned therein for a substantial (e.g., 1 year or more) amount of time, usually against his/her will.

Normalization relates to the belief that an individual should be allowed to live his/her daily existence in a style that is similar to those in the surrounding culture as is sex and age appropriate. In the developmental disabilities field this principal is widely subscribed to even for the most profoundly developmentally disabled person. It is felt that even if the developmentally disabled person has a limited self-awareness of his/her existence in space and time, the normal population which comes into contact with the developmentally disabled person will be more likely to treat the individual as a human being if he/she at least look similar to themselves (Mercer, 1973). Most developmentally disabled persons are sensitive to people in their environment and the response of those who interact with them is an important learning stimulus. If persons in their environment react to them as distorted or as non-normal, then this becomes a negative interaction which puts both the developmentally disabled person and the normal person in an uncomfortable position.

Deinstitutionalization is a process which can be employed as part of a movement toward normalization of a given institutionalized population of people perceived as deviant. The feeling is that if these people are housed in such a style that is normal for their culture, then surrounding citizens are more likely to relate to them as normal. Also, living in the "community" in itself stimulates the individual to learn to cope, thus encouraging the normalization process by making certain learning

demands on the individual. Therefore, it could be said that deinstitutionalization is a tool of normalization.

Neither concept is static. It is part of a normalization process to move an older individual from a diet of baby food to one of soft foods which still require the use of cutlery to break the food into bite size pieces even though this is still not a normal diet because it does not include such difficult-to-eat foods as chicken or steak. It is part of the deinstitutionalization process to move a patient from a psychiatric hospital to a sheltered care facility in an urban area even though that may not be the residential form which is culturally appropriate for the area. Both of these situations are formatively evaluated as positive moves. The person is being helped toward a goal that involves greater participation in the larger "normal" social structure. At least some stigma of the disability has been removed, or covered up. The individual has been moved into a more challenging, demanding situation which is likely to stimulate further positive responses. It is accepted by most human service professionals that there is a limit to this process for many clients which is short of full, stigma-free participation in the culture.

Deinstitutionalization of individuals who have been in a residential facility for a significant period of time is a measure which will redress past injustices by replacing or augmenting custodial goals with ones which are developmental in nature. The establishment of a responsive residential environment is crucial to optimize normalization. The crisis which any geographically mobile person experiences is accentuated for the older developmentally disabled person who has been socialized into a more structually different institutional environment (Cherington and Dybwad, 1974). Considerable help may be required to teach life skills necessary for survival in the community (Hawkins and Folsum, 1975).

A more direct approach is one which is geared toward the prevention of admissions to full-time custodial residential institutions in the first place. This approach is analagous to the maintenance of health rather than the treatment of sickness and disease. It requires the integration of support systems at an appropriate pace for the developmentally disabled child just as the public school system is appropriately paced for the age-graded development of the normal child toward economic and social self-sufficiency. This implies the necessity for community-based institutions which interface with the family and maintain developmentally disabled individuals in a normalized family and community environment throughout their entire life cycle. In the absence of a comprehensive social system designed to maintain the developmentally disabled as full participants in the community throughout their lives, an obvious place to begin to develop such models is with the actual experiences of families of developmentally disabled persons themselves.

Family Integration. Structurally the family is a unit which performs the functions of nurturance and control to enable the child to survive and avoid the hazards of the environment. Performance of the nurturance and control functions is facilitated or impeded by both the activity level of the child and the availability of assistance with the child's care. As

these maintenance functions are fulfilled more easily then the emphasis on emotional bonds becomes more important. Healthy families provide emotional gratification and self-esteem based upon recognition of and affection for the unique individual strengths of each member, rather than the impersonal competitive criteria of the marketplace. The family is an interaction process in which individuals learn and practice roles appropriate for life cycle development. The degree to which families optimize emotional gratification and self-esteem depends upon the relative ease with which maintenance functions can be fulfilled. As maintenance functions are fulfilled, family members are enabled to participate in the usual activities of their relevant social networks. Family integration can be defined as "bonds of coherence and unity running through family life, of which common interests, affection, and a sense of economic interdependence are perhaps the most prominent" (Burr, 1973: 208). Family integration, the adequacy of family organization, is a critical factor related to the ability of families to recover from crisis and therefore to their ability to provide a developmentally disabled child with a normalized environment.

Family integration can be operationalized in terms of intra family relationships such as marital satisfaction and degree of affection, family patterns such as size and kinship relations, and external factors such as socioeconomic status and neighborhood composition (Bossard and Boll, 1966). For example, Farber (1959, 1970) has demonstrated a relationship between family integration and the institutionalization of a retarded child. Additional relationships are delineated in the propositional inventory compiled by Goode, Hopkins, and McClure (1971).

Community Resources. Even the birth of a normal child can be experienced as a crisis to the extent that it involves readjustments of other role commitments (Rossi, 1974). Parents have developmental needs just as children do (McBride, 1973). The ease of the role transitions of the parents of a developmentally disabled child, just as for those of the parents of normal children, will be facilitated by anticipatory socialization. Anticipatory socialization can be defined as contact which allows identification with persons functioning in the role. It can be provided by interpersonal contacts and by studying written accounts.

But whereas parents of normal children can rely for some experience upon widely available handbooks such as Dr. Spock or upon primary emotionally intimate contact with friends and kin, the parents of developmentally disabled children are not so fortunate. A parent organization can provide an informative and intimate support group if one can be located (Auerbach, 1968: 180-208). More often the requisite information is provided by secondary unequal-status contact with professionals and specialists, often uncoordinated, uninformed about the complete range of resources available, and unable to supplement diagnoses with specific advice about parenting a developmentally disabled child (Gorham et al., 1975). The most bitter expression of feeling from parents often concerns their being advised to institutionalize their developmentally disabled children rather than assisting them to develop an adequate home adjustment (Zwerling, 1969; Washowitz, 1970). This lack of help can be contrasted with the positive assistance which parents get in coping with medical diseases such as diabetes or leukemia (Kugel, 1976). In addition to the ease or difficulty of

obtaining information and assistance, community attitudes are an important factor. They may mediate, augment, or deemphasize the impact of the label—ranging from revulsion, condemnation, and avoidance to tolerance, altruism, love, and hope. Identifying community reactions is as important as ascertaining knowledge about available resources. Public information may be as important as the provision of services (Lippmann, 1976). Understanding the dynamics of family and community processes is essential to the formation of enlightened social policy for the developmentally disabled (Caldwell and Ricciuti, 1973).

Rationale

The rationale behind the approach to the problem is derived from three sources. The first source is the demands of the research question itself. In order to understand the choices parents make in securing services for their developmentally disabled child it is necessary to construct a quantitative profile of their needs and resources as perceived by themselves. Current planning efforts for developmentally disabled services have addressed professional service providers' perception of need. However, the providers are not the group of people who make the original choice regarding the services needed by individual children and their families. It is the parents who act on the subjective and objective information available to them in order to secure care for their child. A great deal of decision making has already ocurred before the service provider is introduced to the situation. It is felt that a better understanding of the parent's decision making that is derived from a significant number of parents will be of value in an effort to serve those parents' needs.

The second source of rationale for this study related to the study site. Lake County, Illinois has a wide range of services for developmentally disabled persons that includes both residential and community based programs. Although the county has a diverse population and a wide range of services, the service delivery system is not as complex as would be found in a large urban area such as Chicago. This expedited efforts to select an appropriate sample of parents and understand the available network of services in use.

A third source of rationale for the approach to the problem related to the timing of events in the proposed sample area. Various local efforts to plan services for developmentally disabled persons are mandated by the Developmental Disabilities Services and Facilities Construction Act (P.L. 91-517). In most areas of Illinois this planning effort begins at the sub-region level. However, within sub-regions 7/D.D. (Lake, Kane, McHenry, and part of Aurora Counties) the planning efforts had been brought down to the county level. The most active county within this sub-region was Lake County. Many of the consumers and service providers in Lake County had become interested in developing a data base regarding the needs/wants of service consumers in their area. Because of this they encouraged the conduct of research. We received complete cooperation from all relevant interests in Lake County.

The context of the project is within the deinstitutionalization movement

to provide normalizing environments for developmentally disabled children. It is specifically concerned with the prevention of admissions to residential institutions which require separation of these children from their families and communities. Although we recognize other significant variables, such as the courts and legislation, we believe the major variable is parental attitudes and behavior. Parental backlash can be answered only by demonstrating alternative ways to implement the goals of security and support over the entire life cycle of developmentally disabled individuals. To the extent that parents are meeting these goals without resorting to institutionalization, their strategies can be generalized for others.

If new admissions are to be deflected, it is necessary to deal directly with parents. To provide optimal counseling and support, we must have knowledge of family needs and how they can be met by existing resources or by creating new resources given existing budgets and models of care.

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RESEARCH METHODOLOGY

In order to conduct original research on the decision making process of parents whose children have developmental disabilities, a project was undertaken for the period beginning July 1977 with funding for two years from the Extramural Research and Developmental Grants Program of the Illinois Department of Mental Health and Developmental Disabilities.

The study was conducted in Lake County, Illinois. The county is in close proximity to Northwestern University, which minimized travel time and expense. Lake County offers a wide range of services to developmentally disabled persons. There is a major state-operated residential center for severely and profoundly retarded persons. There are other smaller residential programs operated by private non-profit groups. The county is known for its comprehensive programs of special education offered through the public school districts. There are several sheltered workshop facilities for developmentally disabled persons. Within the area alternative residential programs for developmentally disabled persons are beginning to be developed (e.g., community living facilities, foster home networks, group homes). The county contains people of a wide range of socioeconomic, ethnic and racial backgrounds. Programs are relatively new and expanding. Lake County therefore provided an ideal situation in which to initiate the study of parental decision making.

The area of Lake County was selected for the research population because: (1) it is geographically compact yet includes urban, suburban and rural populations; (2) it offers a wide variety of services for the developmentally disabled; (3) providers and consumers of developmentally disabled services have a history of cooperation with past efforts to secure related information, and (4) the county contains people of a wide range of socioeconomic, racial and ethnic backgrounds.

Sampling was not necessary because the population and delivery system was small enough to include all families and all service providers.

Depth Interviews

An earlier study, conducted during the Summer of 1976 under a grant from the Russell Sage Foundation to study early childhood socialization practices, provided data which informed the present study. One aspect of that research project involved conducting focused group interviews with parents of children regularly receiving child care services outside the home. The interviews involved discussions of several aspects of parental child care decision making: the initial decision to have children cared for outside of own homes, the decision to have children enrolled in present placement, satisfaction and dissatisfactions with the alternative selected, types of social environment desired, and their participation in center activities.

Twelve group interviews were conducted, ten with parents whose children were in centers serving normal children, and two with parents whose children were in centers for the developmentally disabled (Park School, a program for the trainable mentally handicapped in Evanston, and Waukegan Developmental Center, a State-operated residential facility for the training and care of

severe and profound developmentally disabled persons).

Because the number of interviews was small, the results of this study were regarded as exploratory. However, a dramatic difference in the decision making processes of the two groups of parents was noticed as they sought out appropriate services for their children. Because the general public's experience interacting with developmentally disabled persons is very limited, the parents of these children were not able to avail themselves of the usual networks of information (i.e., from parents, friends, neighbors) regarding children's services, networks that are available to parents of "normal" children. As a result of this information vacuum, the advice of the family's primary physician took on an added weight. Often this information complicated the parents' decision making process due to its highly technical nature and the physicians' ignorance of the child's future potential and the current delivery system of developmental disability services. These exploratory interviews indicated that these parents were confused, isolated and perceived themselves as inadequate to make an appropriate choice of services for their developmentally disabled child. If the situation is as serious as this exploratory research indicated, then it seemed necessary to study the issue on a larger scale to define the situation more clearly and to indicate some feasible course of action that would assist parents attempting to make an appropriate choice of services for their developmentally disabled child.

It was decided to conduct additional depth interviews with individual families to explore more fully the decision making process when seeking services for a developmentally disabled child. It was felt the depth interviews would provide detailed information about the resources and service gaps in Lake County itself thus adding important information to a review of the literature for informing construction of the quantitative mail survey questionnaire. An opportunity to contact parents for this purpose was provided through the Lake County D.D.S.A. Planning Group.

In September 1976 members of the Lake County D.D.S.A. Planning Group developed and sent out a four-page questionnaire to approximately 500 families identified as having one or more developmentally disabled children. The survey listed community services utilized by developmentally disabled persons and their families—educational, residential, recreational, transportation, supportive, and health—and asked parents to identify services being used presently as well as services they expected to need for their children within the next five years. At the end of the questionnaire an item was included which asked, "Are you willing to answer additional questions in the future regarding the needs of developmentally disabled persons?" Space was provided for positive respondents to include their name, address, and telephone number. Individuals responsible for the development of this survey provided this project with both letters of support, and the names, addresses and telephone numbers of parents willing to be interviewed, along with the ages of their developmentally disabled children, and the nature of the disability. Ten families to be interviewed were selected so as to provide variation in the nature of the developmental disability and the age of the children for whom services were sought. Parents of mentally retarded, autistic, and epileptic children ranging in age from fourteen months to twenty years old were interviewed, including both black and white families.

At this point the interviews did not seem to be providing further new

major insights, but we realized that all our interviews had been conducted with intact two-parent families. Since we felt that experience of single parents might be significantly different insofar as they had less economic and interpersonal resources than two-parent families, we utilized our own networks to locate two single parents, both mothers, who agreed to be interviewed. One resided in Lake County, the other in Evanston which is in Cook County. Because we were focussing on the single-parent experience, the factor of geographical residence did not seem a major variable for this purpose.

We conducted a total of 14 depth interviews covering: (1) the nature of the child's developmental disability, (2) services which have been used and are expected to be used in the future, (3) how the current day or residential program was chosen, (4) satisfactions and dissatisfactions with these services, and (5) the effect of having a developmentally disabled child upon the family. The interviews, ranging in length from two to six hours, were all tape recorded. The typed single-spaced transcripts range in length from 18 to 53 pages.

Review of the Literature and Identification of Major Subject Areas

A computerized review of the literature was conducted through Northwestern University Library Computer Assisted Information Service (NULCAIS) for a variety of descriptors related to developmental disabilities such as: exceptional child education, research and services, handicapped children, educable and trainable mentally handicapped, retarded children, autism, cerebral palsy, mongolism, epilepsy, mental retardation, regular class placement, institutionalized persons, learning difficulties, low achievers, residential programs, special education, parent education, community programs and involvement, normalization, labeling (of persons), grouping (instructional purposes).

Hundreds of books, articles and reports were identified and their abstracts screened for reference to parental or community attitudes and involvement. These relevant publications were obtained and 47 pages of brief notes compiled listing major concepts, theoretical relationships, and empirical findings.

Data from the review of the literature was integrated with that from the depth interviews to develop a 7-page list of major subject areas and an item pool, 87-page list of related potential items for the questionnaire.

Development of the Survey Questionnaire

The computerized review of the literature and open-ended depth interviews with parents were used to construct a mail survey questionnaire. The questionnaire was pretested with 66 families of children attending three schools for the developmentally disabled in Evanston, Illinois. The City of Evanston, in Cook County, was selected for the pretest because of its proximity to Northwestern University and to Lake County.

The questionnaire was sent home in the children's lunch boxes along

with a cover letter from the director (at the two private schools) or president of the parents' association (at the public school). Parents were asked to return the completed questionnaire in an attached self-addresed stamped envelope, and were given about a week to do so. The participating schools and return rates were as follows: Park School, Public School District #65, 32/59 = 54%; Rimland School for Autistic Children, 14/19 = 74%; and, Shore School (North Shore Association for the Retarded), 18/42 = 43%. An additional 2 questionnaires were returned on which the name of the school was not specified for an overall response rate of 66/120 = 55%.

The returned questionnaires were coded and keypunched and a file defined for statistical analysis of the data with the Statistical Package for the Social Sciences (SPSS) system of computer programs. The data was cleaned by eliminating out-of-range errors and performing a series of contingency checks. An examination of the frequency distributions as well as the respondents' written comments revealed ambiguities in question wording, and difficulties with format. Changes were accordingly made for the final target population in the Lake County mail survey questionnaire.

Following revisions based upon the pretest results, a 57-page mail survey questionnaire was developed for the Lake County population. Structured closed-ended questions were designed to provide data regarding:

--the manner in which parents first discovered that their child was developmentally disabled;

--the availability of extended family and community support networks for the parents and their children;

--the nature of the developmental disability, skill levels, and kinds of limits the children have;

--the manner in which parents successfully or unsuccessfully secure the community services needed by their developmentally disabled children;

--the current professional intervention encountered and its perceived value;

--parents' attitudes regarding the direct services currently used for their children;

--parental involvement in their children's educational programs and organizations concerned with developmental disabilities;

--parents' opinions about general policy directions for the provision of services for the developmentally disabled in their community; and

--long-term plans and objectives these parents have for their children.

The Research Population

The population was defined as Lake County, Illinois, parents of develop-

mentally disabled children ages 0-21 who receive services in Lake County. For the purposes of this study, developmentally disabled was defined as children handicapped by mental retardation, cerebral palsy, epilepsy, autism, or multiple handicaps involving one of the foregoing, and whose handicap required more than 50 percent time in a special education program. The stipulation regarding percent of time in special education was imposed to reduce the number of so-called "six-hour retarded children." The "six-hour retarded child" is a phrase coined to depict the culturally deprived child whose developmental delays occur only in the area of school performance. Our definition restricted the families, insofar as possible, to those having children with physiologically-based disabilities.

Data Collection

Because federal law (P.L. 94-142) requires that all developmentally disabled children between 3 and 21 years must receive a free appropriate education, and because early intervention programs provide services to the 0 to 3 year old age group, records on all children are kept by special education public and private agencies.

Because of school administrators' interpretation of regulations governing rights of privacy, mailings requesting parents to consent to participate in the study went out through the educational facilities serving Lake County: three special education school districts, a state residential facility, a federally funded early intervention program, and six private facilities. Cover letters were included with the signature of the superintendent, principal, or director. Due to the low percentage of consents received after the first mailing (37.7 percent) these educational facilities also conducted a follow-up mailing. Essentially the researchers became a third party to their own research project. No listing of the population was available for follow-ups to estimate the bias introduced by non-respondents. In future studies, every effort should be made to avoid the use of consent forms mailed prior to questionnaire distribution and to obtain a listing of the population utilized for sampling purposes.

The 57-page questionnaire in booklet form was mailed to each family (61.0 percent) who finally consented to participate. Included with each questionnaire mailed was a return postcard which respondents were asked to mail separately at the same time they mailed the completed questionnaire. The questionnaires themselves were filled in and returned anonymously. A follow-up letter with a second return postcard was sent approximately one month later if we had not received a postcard notifying us of its return before that time. These procedures resulted in the return of 330 completed questionnaires (43.9 percent of the families identified and contacted; 72.1 percent of the families who consented to participate).

By the time the four mailings were conducted (two for informed consents and two for the mail survey questionnaire) time and money allocated for data collection were exhausted. Names and addresses were available for those families who consented and then did not respond, but the budgetary constraints precluded telephone follow-ups with this group. With the initial mailing

of consent forms occurring in January 1978, the follow-up mailing to consenting families who had not returned questionnaires was not completed until June 1978, at the end of the school year.

Consent and Response Rates

Consent and response rates varied depending upon the type of special education facility in which a child was enrolled (see Table II-A). The lowest rate of questionnaires completed occurred in the urban special education school district (Waukegan, Illinois), whether completion rates are calculated on the basis of families originally contacted or on the basis of families who consented to participate in the survey.

Demographic questionnaire items made it possible to compare seven characteristics of respondents to 1970 census characteristics of the entire Lake County population as well as the city of Waukegan subpopulation (see Table II-B). Waukegan contains a larger concentration of low income families and of minorities than is true for the county as a whole, which probably accounts for its lower response rate. In general, our sample seems to be fairly representative of the Lake County population in terms of range of social and economic characteristics, except to overrepresent minorities, high school graduates, and single-parent families.

Table II-A

Lake County, Illinois families with developmentally disabled children 21 years of age and under identified, consenting to participate in survey, and returning survey questionnaire

Educational Facility	Families contacted (N)	Families who consented to participate (N)	% of those contacted	Families who returned surveys (N)	% of those contacted	% of those consenting
Special Education School Districts						
Waukegan	(274)	(141)	51.5%	(73)	26.6%	51.8%
NSSED*	(77)	(45)	58.4	(35)	45.5	77.8
SEDOL**	(214)	(154)	72.0	(118)	55.1	76.6
State Residential Facility						
Waukegan Developmental Center	(29)	(21)	72.4	(18)	62.1	85.7
Federally Funded Early Intervention						
Lake-McHenry Regional Program	(70)	(39)	55.7	(33)	47.1	84.6
Private Facilities						
Countryside	(10)	(5)	50.0	(5)	50.0	100.0
Glenkirk	(7)	(6)	85.7	(6)	85.7	100.0
Grove	(22)	(22)	100.0	(19)	86.4	86.4
Klingberg	(2)	(2)	100.0	(1)	50.0	50.0
Lambs	(1)	(1)	100.0	(1)	100.0	100.0
Moraine	(3)	(3)	100.0	(2)	66.7	66.7
Out-of-County Facilities Identified through Special Education School Districts						
Waukegan	(2)	(2)	100.0	(1)	50.0	50.0
NSSED*	(15)	(10)	66.7	(7)	46.7	70.0
SEDOL**	(25)	(7)	28.0	(5)	20.0	71.4
Missing Data	____	____	____	(6)	____	____
TOTALS	(751)	(458)	61.0%	(330)	43.9%	72.1%

* Northern Suburban Special Education District
**Special Education District of Lake County

Table II-B

Comparison of Respondents' Characteristics with 1970 Census Data for Lake County, Illinois and Waukegan Populations, and for Waukegan Black and Spanish-Language Subpopulations

	Lake County		Waukegan					
			Total Population		Blacks		Spanish Language	
	Families Responding	1970 Census	Families Responding	1970 Census	Families Responding	1970 Census	Families Responding	1970 Census
1) Percent Minority								
Black	11.3	5.2	25.5	12.8	---	---	---	---
Spanish Language[a]	3.1	2.9	10.2	7.2	---	---	---	---
2) Percent living in county/community for 5 or more years[b]	66.1	64.4	74.2	79.8	64.0	76.8	70.0	70.4
3) Mdn school years completed[c]	12.0	12.5	12.0	12.2	12.0	10.4	8.0	8.4
4) Percent high school graduates[d]	80.4	63.3	68.0	56.7	60.0	33.7	20.0	24.1
5) Mdn family income								
(1969)	---	$13,009	---	$11,478	---	$8,500	---	$8,641
(1978)	$17,823	---	$15,632	---	$10,333	---	$13,500	---
6) Percent school-aged children in single-parent families/ households[e]	13.6	11.3	22.7	15.9	52.0	34.8	30.0	8.1
7) Percent mothers of school-aged children in labor force[f]	47.9	40.4	58.1	50.3	60.0	70.9	50.0	44.9
N =	(330)		(98)		(25)		(10)	

[a]Respondents identified themselves as "Latino"; 1970 Census reports figures for Spanish language minority group.
[b]Respondents identified length of time they had lived in their current city or town of residence; the Census categories of "living in same house" and "different house, same county" were combined.
[c]Respondents identified level of schooling completed for child's mother; Census data reports figures for all adults 25 years of age and older.
[d]Respondents reported for child's mother; Census data for all adults 25 years of age and older.
[e]Respondents reported for children 21 years of age and under; Census data reports figures for children under 18 years of age.
[f]Respondents reported for children 21 years of age and under; Census data reports figures for women with own children 17 years of age and under.

III.

LABELING AND COMPETENCY

A. CATEGORICAL LABELING

For as long as people have noticed differences, talked about them and written about them, labels for categorizing others have existed. Some of the differences are visibly obvious, such as age, sex, and race (see Tables III-A to III-C for the distributions of these characteristics in our sample). For the population in general, expectations regarding the competencies of adolescents are very different than the expectations for preschoolers. The developmental needs of children and their families correspondingly differ according to the children's ages. Any examination of decision-making concerning needs of developmentally disabled children must take their age into account. Expectations may also differ according to the sex of the child. Parents may encourage boys to be more aggressive, and correspondingly place more restrictions on the activities of girls. Family patterns and associated child-rearing practices and expectations differ between racial and ethnic groups. These three ways of categorizing all children—age, sex, and race—are important because the associated expectations may be important for developmentally disabled children as well.

At the time the survey questionnaire was mailed to Lake County parents, in 1978, developmental disabilities were defined as meaning a disability of a person, under 22 years of age, attributable to mental retardation, cerebral palsy, epilepsy, autism, or multiple handicaps involving one of these conditions. For the most part (in 298 out of 330 cases, see Table III-D) children had been diagnosed and provided with special education services on the basis of these categorical definitions and the parents in our sample were able to report the labels (mental retardation, cerebral palsy, epilepsy, autism) associated with their children's disabilities. For the 32 cases where no label was reported, the missing data could have been accounted for in several ways: the question could have been inadvertently skipped, parents might never have been informed of the categorical label for the disability, or parents might be denying the appropriateness of a label. We assumed that it was more likely a parent either would not know or would be unwilling to report the label if a child was mentally retarded than if the child had cerebral palsy, autism, or epilepsy. Amongst the mentally retarded it seemed plausible that the less severe the retardation the more likely the parent would be to deny the applicability of the label preferring instead to think of the child as merely "a little slow in school." For these 32 cases, parents did answer questions about the functional abilities of their children. Our hypothesis that the children would be amongst the most capable was not substantiated; their functional disabilities were distributed across all levels (mild, moderate, severe and profound) in a nonsystematic fashion. For subsequent analyses, the 32 cases were classified in the intermediate, mental retardation—moderate, category.

The meaningfullness to parents of standardized intelligence test scores has been questioned by professionals and advocates alike. The child's ability to function on a day-to-day basis is regarded as more important. The majority (64.1 percent) of parents had not been told their child's IQ levels (see Table III-E). Among the parents who had been told, the IQ scores reported were consistent with the American Association on Mental Deficiency's determination of levels of mental retardation using ranges for the Stanford-Binet and Cattell intelligence tests. Whether or not parents had been told their

children's IQ scores differed by age of child, type of child's disability, family income, and race.

Age of Child. Parents of preschool children were much more likely to report that professionals did not know what their children's IQ scores were (47% versus less than 10% of parents of older children).

Type of Disability. Only in the case of mildly retarded children did a majority (71%) of parents suspect that professionals knew their children's IQ scores but had not informed the parents.

Family Income. Parents in higher income families were more likely to know their children's IQ scores. Therefore, fewer high income parents suspected that professionals knew but had not informed them.

Race. Minority parents were more likely to suspect that professionals knew their children's IQ scores but had not informed them (75% of Latinos, 66% of blacks, and 44% of whites).

Table III-A

Age of Developmentally Disabled Child*	
Preschool (birth to 5 years old)	23.5%
Primary (6 to 12 years old)	31.3
Secondary (13 to 18 years old)	30.7
Transitional (19 to 21 years old)	14.6
	N=323

Table III-B

Sex	
Male	57.3%
Female	42.7
	N=323

Table III-C

Race	
White	85.4%
Black	11.2
Latino	3.4
	N=321

*If there was more than one developmentally disabled child in the family, the parent was requested to answer the survey questionnaire for the oldest developmentally disabled child. N's are less than 330 due to missing data on certain questions. Totals may not equal 100.0% due to rounding error.

Table III-D

Type of Disability*	
Mental retardation - mild	21.5%
Mental retardation - moderate	33.9
Mental retardation - severe and profound	20.1
Cerebral palsy	11.7
Autism	3.7
Epilepsy	9.1
	N=298

Table III-E

I have been told that my child's IQ is . . .	
Untestable	6.8%
35 or below	5.2
Between 36 and 55	9.1
Between 56 and 70	9.4
Between 74 and 85	3.9
86 or above	1.3
Professionals don't know what my child's IQ is	16.9
Professionals may know, but I have not been told	47.2
	N=307

*When children were reported as multiply handicapped they were categorized by type as follows: (1) mental retardation and epilepsy--categorized under epilepsy, (2) mental retardation and cerebral palsy or mental retardation, cerebral palsy and epilepsy--categorized under cerebral palsy.

B. FUNCTIONAL ABILITIES

Categorical labels such as "mental retardation," "cerebral palsy," "epilepsy," and "autism" have become a commonly-used shorthand for designating those developmentally disabled requiring services. Parents and professionals have raised a number of questions about the utility of these labels. Individuals within the categories may exhibit a wide range of abilities and disabilities. Stereotypes, often based upon the most severely disabled within the categories, may become attached to the labels. Economically or culturally disadvantaged children may be erroneously labelled as mentally retarded. To overcome these difficulties noncategorical definitions, based in part upon functional limitations, have been proposed. A number of measures of functional abilities in task areas (Table III-F) and measures of health assessment (Table III-G) were included to provide a more comprehensive view than the categorical labels alone would provide.

1. Functional Abilities in Task Areas

A bare majority (55-58%) of children have mastered basic self-care activities (see Self-Care section of Table III-F). Basic communication skills are more variable (see Receptive and Expressive Language section): approximately two-thirds easily handle giving and receiving affection, and understand when spoken to;slightly less than half easily handle looking at people when spoken to or greeting people by saying hello; about one-third speak clearly or at the proper volume; only one-fifth shake hands when meeting someone for the first time. Few have mastered written language skills or achieved the capacity for independent living.

Age of child. As would be expected, most children's functional abilities improve with age. The exceptions are worth noting. First, the ability to give and receive affection is the only measure to remain constant over the life cycle. Second, the abilities to read, to write, and to use public transportation alone peak in the secondary school-age group (13 to 18 years old), dropping off in the transitional group (19 to 21 years old). We interpret this to mean that the higher functioning young adults would not require or desire an extended period of time in high school.

Type of Disability. Degree of mental retardation is related to a systematic way to all of the functional abilities measured. In general, children with epilepsy resemble those in the moderately retarded category. The single exception is the ability to ride public transportation alone (only 4% are reported as handling this easily). This is likely due to lack of predictability of seizure activity rather than physical or cognitive limitations. In general, children with cerebral palsy or autism resemble the severely and profoundly retarded. In those cases where the physical disability would not be as likely to affect performance, those with cerebral palsy are more like the mildly retarded: looking neat, giving and receiving affection, and looking at people when spoken to. Children with autism are far less likely to give and receive affection than the severely and profoundly retarded (27% compared to 58% are reported as handling easily).

Family Income was not associated with any of the functional abilities. Lack

of any statistical associations for this variable supports our assumption that the operational definition of developmental disabilities used for the study resulted in a relatively pure sample of mentally and physically impaired children. That is, there was no overrepresentation of the economically disadvantaged.

Race. On all but two of the measures, more blacks were reported as handling functional tasks more easily than were whites (giving and receiving affection, and shaking hands when meeting someone for the first time). For example, two-fifths of black children were reported as reading and writing simple sentences easily as compared to one-fifth of white children. For some black children special education may be a remediation for cultural disadvantages.

2. Measures of Health Assessment

The majority of the developmentally disabled children in our sample are perceived by their parents as being as healthy as normal children (see Table III-G). Physiological health measures (general health, catching colds, and tiring easily) are normally distributed, with about the same proportion of children having more problems than normal children as having less problems. Where a physiological problem would necessitate the child communicating the problem to the parent, developmentally disabled children are actually perceived to have less problems than normal children. Thus 40.6% are reported as complaining less often of aches and pains, and 33.4% are reported as less fussy about what they are willing to eat. With respect to unusual behaviors such as headbanging, a majority (51.4%) are reported as never engaging in this type of behavior; only 8.7% are reported as engaging in this type of behavior often. Slightly more than one-quarter of the children had ever had a seizure (29.3%) or were taking medicine regularly (27.8%).

Age of Child. Age of child has little effect on developmentally disabled children's health. Statistically significant relationships were only found for catching colds and fussy eating habits; the problems declined as the children matured. There was a tendency for use of medication to increase as children became older (21% of preschool children as compared to 33% of 19 to 21 year olds).

Type of Disability. Even though the number of cases is small (N = 11) children with autism were strikingly different than the other children. Compared to normal children, no children with autism were reported as having generally poorer health, catching colds easily or being fussy about what they will eat. The latter is especially interesting because of the frequent emphasis on food fetishes as one of the distinguishing symptoms of autism. Of the children labeled as having epilepsy, 100% were reported as having seizure activity (validating the label). Perhaps of greater interest, 61 of the other children--labeled mentally retarded, cerebral palsy or autistic--were also reported as having seizure activity. Of this group, more seizure activity was reported among the more severely disabled. Seizure activity was reported for only 12% of the mildly mentally retarded and 14% of the moderately mentally retarded compared to 39% of the severely and profoundly mentally retarded, 40% of those with cerebral palsy and 36% of

those with autism. The actual incidence of epilepsy may be masked by other labels which are given diagnostic precedence. Medication is not being utilized for behavioral control, but rather is associated with the severity of the disability. Few of the mildly and moderately retarded take medication regularly (12% and 14%, respectively). The incidence rises for severe and profound retardation (38%), cerebral palsy (40%), autism (54%), and epilepsy (85%).

Family Income is not systematically associated with any of the health related measures except manifestation of unusual behaviors. Children from low income families are more likely to do unusual activities such as head banging, rocking and clapping. Less enriched environments may encourage such self-stimulating activities.

Race is not related systematically with any of the health related measures.

Functional Abilities in Task Areas	Handles Easily	Does With Difficulty	Cannot Do	
Self-Care				
Self-care activities: for example, goes to toilet without help, gets dressed, feeds self.	55.4%	28.2	16.5	N=327
Eats properly.	55.0%	37.8	7.2	N=320
Looks neat.	58.3%	39.6	2.2	N=319
Receptive and Expressive Language				
Gives and receives affection.	67.6%	31.1	1.2	N=321
Understands when spoken to.	63.9%	30.2	5.9	N=324
Looks at people when spoken to.	46.7%	49.6	3.8	N=319
Greets people by saying hello.	45.0%	30.6	24.4	N=320
Speaks clearly enough to be understood.	35.6%	35.9	28.5	N=326
Speaks at proper volume.	33.2%	40.8	25.9	N=313
Shakes hands when meeting someone for the first time.	21.8%	43.6	33.6	N=321
Learning				
Reads simple sentences.	24.8%	14.5	60.7	N=323
Writes simple sentences.	20.5%	13.3	66.1	N=322
Capacity for Independent Living				
Organizes activities for self: for example, turns on TV, picks up book or magazine, suggests playing a game.	58.4%	17.7	23.9	N=327
Knows how to behave properly in different settings.	36.8%	52.1	11.2	N=321
Self-help skills: for example, shops, picks out the right clothing for the weather or event, prepares some meals, handles money.	22.8%	25.2	52.0	N=325
Rides public transportation alone.	15.8%	4.7	79.5	N=317

Table III-G

Child's Health				
Compared to Normal Child's	More Than Normal	About the Same	Less Than Normal	
Must be watched closely because of generally poor health.	15.7%	65.8	18.5	N=313
Catches colds easily.	23.2%	62.1	14.7	N=319
Gets tired easily.	20.7%	61.1	18.2	N=319
Complains of aches and pains.	9.5%	49.8	40.6	N=305
Very fussy about what she/he will eat.	17.0%	49.5	33.4	N=317
Manifestation and Treatment	Often	Sometimes	Never	
Does unusual things like head-banging, rocking, clapping.	8.7%	40.0	51.4	N=321
			% Yes	
Has your child ever had a seizure (convulsions, spells, or fits)?			29.3%	N=324
Is your developmentally disabled child taking medicine regularly?			27.8%	N=324

C. THE SOCIAL WORLD

The home is the ideal place for learning to interact with normal children and adults through the effective use of leisure time. Type of participation in routine household activities will affect the number of skills learned. Participation also teaches the value of constructive use of leisure time. The more opportunities provided through the home for interaction with relatives and neighbors, the more normalized the child's environment becomes.

Social interactions with others may be limited or encouraged by the child's parents or own personal preferences. Approximately 60% of all the children are restricted to the house or yard when they are unsupervised (see Table III-H). However, the child's mobility without supervision is, as would be expected, highly associated with age and type of disability. By the age of eighteen to twenty-one years only 31% are restricted to the house or yard if they are not supervised. As the severity of the child's disability increases, so does the amount of supervision. More than 90% of the children do watch television (Table III-I). One-third of them have the amount of TV viewing time monitored by their parents. Whether or not parents place limits on the amount of time spent watching TV is not associated with either the child's age or type of disability except for the very youngest and most severely disabled who do not watch TV. The extent of interactions with other children is rarely limited by the child's own preferences (Table III-J). Only 5% prefer to be alone rather than with friends and almost two-thirds have no friendship preference because they enjoy being with everyone.

Outside of school, the vast majority are engaged in meaningful activities--such as doing homework and chores, engaging in family activities or watching TV (Table III-K). Very few are often just wandering aimlessly (6%). Brothers and sisters are the most frequent playmates, followed by unrelated normal children, and then by cousins or other relatives (Table III-L). Less than one-third spend time outside of school with other developmentally disabled children. The family and community do provide a "mainstreaming" or normalized environment. Ninety percent have the ability "to get along nicely" in their interactions with these playmates (Table III-M). About one-third do have difficulty in terms of concentrating on and initiating activities.

Age of Child. Social relationships do change significantly over the life cycle. Amount of time spent in activities with parents, siblings and other relatives decreases dramatically. For example, 63% of the preschool children were often engaged in activities with family members compared to only 23% of the transitional group. Correspondingly, over the life cycle more children in each subsequent age group spend time watching TV and with other developmentally disabled children. The older the child, the more constricted the social world seems to be.

Type of Disability. Severity of the disability is associated with social relationships in a predictable fashion. The mildly retarded have the most extensive social contacts and capabilities. Children with autism have the least.

Family Income. On most of the dimensions investigated, family income is not

associated with social relationships. The two exceptions are worth noting. Children from low-income families were much more likely than children from high-income families to help around the home (42% versus 24%) and to spend time with cousins or other relatives outside of school (34% versus 13%).

Race. Children from black families had more social interactions with a wider variety of people and were evaluated as having better interpersonal skills than were children from white families.

Table III-H

Parents usually establish limits to how far a child can go alone. What is the farthest from home your developmentally disabled child may go without supervision?	
Our house or yard only	58.9%
Around our block only	6.5
Across the street	3.1
In our neighborhood only, and may cross street(s)	19.6
All over the community	11.8
	N=321

Table III-I

Watching TV seems to be a favorite pastime for children. Do you limit the number of hours your child spends watching TV?	
Yes	33.6%
No	57.8
It isn't necessary because our child doesn't watch TV.	8.7
	N=277

Table III-J

What kind of friends does your developmentally disabled child prefer?	
Has no preference, likes to be with anyone	62.7%
Younger children	13.9
Children of the same age	9.5
Adults	5.4
Prefers to be alone	5.1
Older children	3.4
	N=295

Table III-K

During the time your developmentally disabled child is at home on a regular week day, what is she/he usually doing before going to bed?				
	Often	Sometimes	Hardly Ever	
Wandering aimlessly; no real activity.	5.8%	20.1	74.1	N = 259
Working on developmental skills, doing homework, or reading.	18.0%	37.2	44.8	N = 266
Helping around home (for example, taking out trash, setting table, sweeping, feeding pets).	28.7%	30.5	40.7	N = 275
Activities with family (for example, games, reading, talking).	51.1%	37.6	11.3	N = 274
Watching TV or listening to radio or record player.	72.6%	18.5	8.9	N = 281

Table III-L

Outside of school, does your developmentally disabled child spend time with:				
	Often	Sometimes	Hardly Ever	
Brothers or sisters?	62.9%	18.1	19.0	N = 310
Cousins or other relatives?	23.2%	29.1	47.7	N = 306
Normal child(ren), not relatives?	31.7%	31.1	37.2	N = 309
Developmentally disabled child(ren), not relatives?	11.1%	19.9	69.0	N = 297

Table III-M

Below are some items about getting along with other children.
Do they describe how your developmentally disabled child gets along?

	Often	Sometimes	Hardly ever	
Has the ability to get along nicely with other children.	65.5%	25.3	9.1	N = 316
Is able to sit down and concentrate on a game.	31.3%	31.0	37.7	N = 313
Can initiate an activity with other children.	31.8%	29.6	38.6	N = 314
My child always wants to have his/her own way.	29.7%	43.8	26.6	N = 313

IV.
NORMALIZATION

A. ATTITUDES TOWARDS MAINSTREAMING

1. Mainstreaming

Theoretically mainstreaming can be conceptualized as a continuum providing developmentally disabled children with an increasing amount of contact with other children. However, parents' attitudes do not seem to be organized in this fashion of increasing or decreasing favorability towards amount of contact provided. Rather their attitudes are bimodal, favoring either separate buildings or a combination of special and regular classes within a regular attendance center. Conversely, there is little support for either total integration or for self-contained classrooms within a regular attendance center. (See Table IV-A)

Slightly over 2/3 of the parents reported that their children were in the type of environment they perceived as most appropriate, although not necessarily in their own community (see Table IV-B). Of the parents who reported that their children were not in the most appropriate environment, virtually all had children who were attending separate schools for the developmentally disabled. Not surprisingly parents of mildly and moderately retarded children were more likely to favor a combination of special and regular classes within a regular attendance center.

Attitudes towards mainstreaming are based upon judgments about both the educational and social needs of developmentally disabled children (See Table IV-C). A majority of parents feel their children learn more in special education classes (82.7%) and would have difficulty getting along socially if all the other children in the program were normal (59.5%). On the other hand, they also feel their children would greatly benefit from meeting more normal children (60.0%). This complex assessment of different needs may account for their ambivalence about the motivation for mainstreaming (see item #5, Table IV-C).

Age of Child. Parents of younger children are more likely to express attitudes favorable towards mainstreaming. This may reflect a more hopeful outlook among younger cohorts and/or that developmental delays are not as accentuated for younger children.

Type of Disability. As was true for feelings about appropriate environments, not surprisingly parents of mildly and moderately retarded children were more likely to favor mainstreaming than were parents of children with severe or profound retardation, cerebral palsy or autism.

Family Income did not seem to be systematically associated with attitudes toward mainstreaming.

2. Parents' Priorities for Programs

Program priorities are clearly child-centered (see items ranked #1-5, Table IV-D), with parents' needs second (see items ranked #6 and 7), and mode of service delivery least important (see items ranked #8 and 9).

Table IV-A

There is a lot of talk these days about "mainstreaming" children with developmental disabilities into programs and classrooms with normal children. Mainstreaming means different things to different parents. If your child were to be mainstreamed into the environment which you felt to be most appropriate for his/her developmental disability, which of the following alternatives would you choose?	
Having child attend a special education program or school for the developmentally disabled located in your community.	47.3%
Having child attend special education classes in the same building as other children attending regular classes.	12.5
Having child involved in some special education classes but also in some classes or activities with normal children.	38.7
Having child involved only in regular classes and activities with normal children.	1.6
	N=313

Table IV-B

Is your child actually in the type of environment which you checked above as most appropriate?	
Yes, in our own community	40.8%
Yes, but not in our own community	27.3
No	31.8
	N=311

Table IV-C

Some parents have made the following statements about mainstreaming. Do you agree or disagree?

	Agree	Uncertain	Disagree	
My child learns more in special education classes than would be possible in regular classes.	82.7%	12.7	4.6	N=307
My child would do better in a special recreation program than in a regular program.	73.3%	14.0	12.7	N=300
My developmentally disabled child would greatly benefit from meeting more normal children.	60.0%	18.7	21.3	N=310
My child would have difficulty getting along socially if all the other children in the program were normal.	59.5%	14.4	26.1	N=299
Mainstreaming is an excuse forcutting back funds for special education.	38.9%	29.6	31.6	N=301

Table IV-D

If you had a choice in selecting your developmentally disabled child's program, how important would the following be in making your decision? (rank ordered by importance of factors)

	Important	Uncertain	Not Important	
1. That my child likes the program.	96.8%	3.2	0.0	N=311
2. That there are support staff available (psychologists, social worker, doctor or nurse, therapists).	96.2%	2.9	0.9	N=313
3. That the program is developmentally sound (small staff/student ratio, regular written progress reports, skills instruction provided).	95.2%	3.2	1.6	N=313
4. That the facility is attractive (clean, well kept-up, have recreational and social areas, provide meal services).	94.9%	3.5	1.6	N=312
5. That the program is easily accessible (within walking distance or with transportation provided).	85.8%	1.9	12.3	N=317
6. That there is an opportunity for parent involvement.	83.9%	10.3	5.8	N=310
7. That I like the staff.	82.9%	6.8	10.3	N=310
8. That other students in the program have developmental disabilities which are about the same as my child's.	78.5%	9.0	12.5	N=311
9. That my child remain in the public school system.	54.4%	20.1	25.5	N=309

B. COMMUNITY ACCEPTANCE

1. Social Distance

Labeling a developmentally disabled child as deviant may result in both the child and the family being isolated from regular social contacts. Increased social distance and isolation can occur as a result of the family's withdrawal from social interactions as well as because others exclude the family and child from their social activities. If parents are willing to initiate social invitations, most (88.6%) perceive their neighbors as willing to accept (see item ranked #1, Table IV-E). Fewer perceive their neighbors as willing to extend the invitation (69.2%), to accept the developmentally disabled child as a friend for their own children (60.3%), or to accept the child as a neighbor living in a community living facility upon reaching adulthood (61.3%) (see items ranked #2-4, Table IV-E). When relationships move beyond neighborliness to collegiality at work, at school and in clubs (see items ranked #5-7), only about 1/2 of the parents perceive their neighbors as accepting their developmentally disabled children. Finally, least acceptance is perceived for relationships which symbolize adult status in the community, opposite sex friendships and voting privileges (see items ranked #8-9). Thus, social distance is perceived to increase as developmentally disabled children move from their own homes, to the neighborhood, to collegial relationships and to full acceptance with all the rights and privileges of adulthood.

Age of Child. Parents of younger children are more optimistic, perceiving less social distance, than are parents of older children.

Type of Disability. The relationships between perceived social distance and type of disability are quite dramatic. Parents of mildly retarded children perceive the greatest acceptance (65-95% think their neighbors would accept their children in the 9 situations presented; interestingly lowest acceptance is perceived for opposite sex friendships). In general, projected acceptance decreases by type of disability as follows: moderately retarded, epilepsy, cerebral palsy, severely and profoundly retarded, autism. A majority (80%) of neighbors of families with autistic children are perceived as willing to accept only an invitation to the parents' own homes. A minority (0-44%) of neighbors of families with autistic children are perceived as accepting of the other 8 types of situations presented.

Family Income. In general, lower income families perceive neighbors as more accepting.

Sex of Developmentally Disabled Child. Invariably, neighbors are perceived as more accepting of developmentally disabled daughters than of sons.

2. Entering Adulthood

Thinking of what their developmentally disabled children will actually be doing upon reaching adulthood at 21 years of age, parents most commonly express either a continuation of familial protectiveness (child remaining at home and having a

job in a sheltered workshop) or independence (child living on own or with friends and having a regular job in the community). (See items ranked #1-2 in Tables IV-F and IV-G.)

Age of Child. As was the case for perceived social distance, parents of younger children are more optimistic.

Type of Disability. The more severe the disability the more likely parents are to choose a community facility as the most appropriate living situation (see items ranked #3-5, Table IV-F). Parents of mildly retarded children are most likely to expect their children to hold a regular job (60.0%). Parents of moderately retarded children project either a sheltered workshop (43.6%) or a supervised job (31.8%) as appropriate. A job in a sheltered workshop is expected by parents of children with autism (88.9%), severe and profound retardation (69.4%), epilepsy (50.0%), and cerebral palsy (42.9%).

Family Income. The higher the income the more likely parents are to project a community facility and a sheltered workshop as most appropriate.

Sex of Developmentally Disabled Child. Females are more likely to be expected to remain at home or to live on their own and to work in a sheltered workshop. Males are more likely to be expected to live in a community facility and to work in a regular or supervised job in the community. That is, females are perceived as needing more protection on the job whereas males are perceived as needing more supervision in their living situation.

Parents' Comments Concerning the Future of Their Developmentally Disabled Child

Concerning her future--I many times hope I out-live her but the future cannot be ignored and must be planned for. We must try to make it as pleasant for the retarded as we can. (#506)

I feel parents of younger handicapped youngsters, that will need supervised living when they are older, should be concerned about the future, now. It's easy to put it off and hope something will be available in 10 or 15 years. It's very hard to get parents to look into the future. This could be because the future is so uncertain--how far will their child develop, what will be available, etc. (#315)

Can't bear to think about it now. Feel we'll cross that road when we come to it; that it is impossible to cope with something that won't occur for 20 years. (#594)

I would like to see all kinds of "care facilities" available so I could place my child in an atmosphere that is "right" for her. It would be unrealistic to put a child who is not self-sufficient in her own apartment or with friends. Then there are supervised facilities--as to what kind of supervision it would of course depend on how independent my child is at that time. I hope by then there are enough "care" facilities available so a parent could make a caring and educated choice and not have to place the child in an unfit area only because it was the only space available. (#590)

I would feel much better about his chances of a job if he received at least ½ day vocational training beginning at the junior high level. This is not true now. He is a good worker. He wants to "get a job". Training is the problem. (#054)

We are very concerned about our child's future financially. Will there be sheltered work shops? Although a number of family members will take our child if anything should happen to us, the financial burden is a great concern. (#134)

Since we very much want our child to live with us, I forsee a pressing need for respite care. As we get older, it may be physically more difficult for us to meet his needs, and any help in this area will be required. (#643)

Help!! There seems to be little, in terms of counseling and information available. (#328)

Table XV-E

Some people with developmentally disabled children find certain communities more accepting than others. Imagine your own child at different stages in life; how accepting do you think your own neighbors are (or would be) in the following situations? They do (would): (rank ordered by frequency with which community acceptance projected)

	Would	Uncertain	Would not	
1. Visit us when child is at home.	88.6%	6.6	4.7	N=317
2. Invite to visit in their own homes.	69.2%	12.1	18.8	N=315
3. Accept as a neighbor living in a community living facility (upon reaching adulthood).	61.3%	29.8	8.9	N=315
4. Accept my developmentally disabled child as a friend for their own children of the same age.	60.3%	18.8	20.9	N=320
5. Accept as a coworker (upon reaching adulthood).	52.2%	32.5	15.3	N=314
6. Accept as a classmate at the same school for their own children of the same age.	51.7%	24.0	24.3	N=317
7. Accept as a member of a social club with their own children of the same age.	50.5%	24.8	24.8	N=311
8. Accept as a friend for their own children of the opposite sex.	46.8%	25.3	27.8	N=316
9. Accept as a voting member of the community with full legal rights (upon reaching adulthood).	42.4%	32.5	25.1	N=311

Table IV-F

Which of the following choices of living situations do you think will be most appropriate when your child becomes 21 years old? (rank ordered by frequency with which living situation expected)	
1. With me at home.	34.0%
2. Living on own or with friends.	21.8
3. A private residential facility (like Grove or Lamb's).	19.8
4. A supervised apartment house unit.	12.5
5. A public residential facility (like Waukegan Developmental Center)	11.9
	N=303

Table IV-G

Which of the following choices of work situations do you think will be most appropriate when your child reaches age 21?	
1. A job in a sheltered workshop.	43.5%
2. A regular job in the community.	32.4
3. A supervised job in a special business program (for example, in a hospital, restaurant, or motel).	24.1
	N=253

C. ANTICIPATED NEEDS FOR RESIDENTIAL CARE

Although few children are old and capable enough to look after themselves (3.3%), not many parents have contingency plans for placement in a supervised facility (10.2%) in the event that they became unable to care for their developmentally disabled children. The majority expect other family members or friends would care for their children (63.0%). The remainder, about 1/5, simply trust to the future or leave placement up to the State. (See Table IV-H.)

Few parents have long-range plans involving a residential placement. Even if the eventual need for such a placement is anticipated, the timing for such a transition is left vague (see item ranked #2, Table IV-I).

Not surprisingly, parents of younger children are more likely to rely on relatives or friends; parents of older children are more likely to have arranged for a supervised facility. The more severe the disability, the more likely a facility is to have been planned.

Parents' Perceptions of Their Child's Need for Residential Placement

The right time is when the family can no longer provide what the child needs effectively--when more help, teaching, etc., is indicated. Family health also should be considered. I feel no one member, retarded or not, should be more important than any other member. However, the retarded person deserves no less than the best opportunity to develop his potential. (#263)

I am looking for a residential home now--My son is 19 and the longer I wait the harder it will be for him to adjust to adult living. It is difficult to find a placement-with waiting lists everywhere we turn-and not much help from outsiders. (#310)

I placed my child 12 years ago because I could not continue to care for her and give her and the rest of the family the necessary time. At that time there were not any programs for after school etc. and I was physically worn down and could not continue as things were. I needed physical help more than anything else. (#776)

We would like, if at all possible, to avoid residential placement, but feel that, realistically, this may have to be considered someday. (#583)

Children who are normal grow up and leave home at about this time. It would be unfair to our child to keep him at home without friends and activities. (#281)

We plan to have our child finish his special education years and then see what the possibilities are for his future. We would like to place him in a permanent home while we are still healthy and able to visit him and have him home for vacations. After his schooling is finished, we feel he will truly miss his friends, all DD individuals, and would be happier in a residential or community living placement before an emergency arises and he has to be abruptly uprooted from home. We don't know at what age this will be. (#508)

Plan to place in early to mid-teens because: 1)We are weary; 2)I feel unprepared to care for a menstruating teen with developmental disabilities; 3)if child is positively going to live elsewhere, this seems to be a fairly natural time to make a transition; 4)considerations of various sorts in regard to adolescent sibling same sex. (#328)

Our child will finish school at 21. Her brother and sisters will most likely not be living at home. He father and I will be in our 50's. I think if a good residential placement could be found it would be to everyone's advantage. I think at age 21, our child will want friends, a social life, etc., that we will not be able to provide and the community cannot provide at this time. (#315).

Table IV-H

Many parents are concerned about what would happen if for some reason they were unable to care for their developmentally disabled child. What do you think would happen to your child if you were unable to care for him/her? (rank ordered by frequency of future type of care anticipated)	
1. A family member or friend would care for child.	63.0%
2. I pray to outlive child; I live from day-to-day and trust the future will look after itself.	13.9
3. I have planned for placement in a supervised facility.	10.2
4. The State would place and care for child.	9.6
5. Child is old and capable enough to look after him/herself.	3.3
	N=303

Table IV-I

If your future plans include residential care for your developmentally disabled child, when do you plan to do this? (rank ordered by frequency with which timing of residential placement planned)	
1. Do not plan residential placement	43.0%
2. Other plans (not specified as to timing of placement)	32.9
3. My child is currently in a residential facility.	11.3
4. When he/she becomes 21 years old.	7.0
5. As soon as we can find a place for him/her.	3.0
6. When our child finishes his/her current day program.	2.7
	N=328

V.

FAMILY INTEGRATION

A. ATTRIBUTION OF CAUSALITY

Parents have different reactions to finding out that they have a child with a developmental disability. Some seek to reorder their lives and expectations by finding out as much technical information as possible. Some wonder if the disability was caused by something they did or something that happened to them. Some are able to accept the disability without searching for reasons. Parents may agree or disagree with the explanations offered by doctors.

Parents were given a list of eighteen causes for their child's developmental disability (Table V-A). They were first asked whether any doctors had mentioned each as possible causes. They were then given the same list and asked how many of these they personally believed were causes. Parents most often responded that doctors did not attribute causation or blame and they tended to concur with this judgment. There is a very slight tendency for parents to blame themselves to a greater extent than doctors are reported to do (Items 6, 8, 9, 10, 12, 13, 14, 16, 17, and 18); and for doctors to provide a non-evaluative medical explanation to a greater extent (Items 2, 3, 5, and 11). For the most part, there is very close agreement reported between doctors and parents. There are two areas where attributions of causality are reported to differ markedly. Parents are more likely to attribute the disability to the will of God than are doctors (37.5% versus 18.8%) and to blame the medical profession for a mistake (17.6% versus 10.4%).

Sometimes after parents learn that a child of theirs is developmentally disabled, they make a decision about whether or not they want more children. Parents were asked to describe their personal thoughts about this decision (Table V-B). The most common responses given indicated that having a developmentally disabled child was irrelevant to decisions about having more children. Approximately two-fifths just wanted more children (Items 1 and 2) and another one-third did not (Item 3). If the developmental disability did make a difference parents were more likely not to want more children. Approximately one-quarter were afraid additional children might be developmentally disabled or that they would not have enough time, energy and money for them (Items 4 and 5). A smaller proportion of parents, one out of every seven or eight parents, wanted more children in order to help the developmentally disabled child or in order to have a normal child (Items 7 and 8). Concerns for the mother's health rather than concerns for the children were the deciding factor for some parents (Items 6 and 9).

Age of Child. The younger the children, the more likely the parents were to have made a decision not to have more children after learning about the developmental disability. It may be that increased emphasis on mainstreaming has made parents more aware of the extra effort a developmentally disabled child will require and more fearful about having additional children.

Neither Type of Disability nor Family Income seemed to be related in any systematic fashion to parents' decisons about having more children.

Table V-4

Attribution of Causality
(Rank ordered by frequency of doctors mentioning causes.)*

	Doctors Mentioned	Parents Believe
1. She/he did not know what caused the condition or said it was not anybody's fault: it could have happened to anybody.	61.8%	60.4%
2. Difficult delivery.	20.4%	19.9%
3. Genetic problems.	20.4%	18.9%
4. The will of God.	18.8%	37.5%
5. A childhood illness or accident.	12.5%	12.4%
6. Baby was premature (or postmature).	11.6%	11.8%
7. A medical or doctor's mistake.	10.4%	17.6%
8. An illness during pregnancy (such as toxemia or rubella).	10.3%	10.6%
9. Mother too old to have had the baby.	7.8%	9.6%
10. Family history of developmental disabilities.	7.8%	9.3%
11. Rh incompatibility.	4.4%	3.7%
12. Drugs, alcohol, smoking during pregnancy.	3.4%	5.0%
13. A fall during pregnancy.	3.4%	3.7%
14. Environmental factors (for example, lead-based paint, mercury contamination).	2.5%	4.3%
15. Did not give the baby enough attention in infancy.	2.2%	1.9%
16. Mother's diet during pregnancy.	1.9%	4.3%
17. Negative or ambivalent feelings about having the child.	1.3%	2.2%
18. A previous abortion.	0.3%	0.9%

*All N's ≥ 319.

Table V-B

Sometimes after parents learn that a child of theirs is developmentally disabled, they make a decision about whether or not they want more children. Do the following describe your personal thoughts about this decision? (Rank ordered by frequency feelings expressed.)*

		Yes, I felt this way.
1.	Just wanted more children.	39.1%
2.	More children wanted, and no reason to think that they would be developmentally disabled.	38.1%
3.	No more children were wanted anyway.	31.2%
4.	No more children wanted because they might be developmentally disabled.	26.4%
5.	No more children wanted because this child needs so much time, energy, and money.	24.8%
6.	I was too old to have any more children.	16.7%
7.	More children wanted in order to help the developmentally disabled child.	14.5%
8.	More children wanted because it was important to have a normal child.	12.3%
9.	Was a difficult delivery; additional deliveries possibly dangerous to my health.	9.7%

*All N's ≥ 317.

B. EFFECT ON SELF AND FAMILY

Having a developmentally disabled child in the family affects mothers and fathers, individually, as well as their marriage. The extra attention that a developmentally disabled child requires can result in either strong bonds of affection or resentment. There may be opportunity costs insofar as the developmentally disabled child requires so many resources—time, energy, money—that other activities have to be curtailed.

1. Effects on Mothers

Most mothers feel that having a developmentally disabled child has been beneficial to them personally (Table V-C, "Feelings" Items 1 and 2). It is also the case that most mothers do not feel adversely affected (Items 3 to 6). When it comes to admitting negative feelings, however, attitudes are likely to be polarized (fewer people express uncertainty). Thirty percent feel uncomfortable leaving their child at home when they go out and about one-tenth admit to sometimes becoming so frustrated they wish the child would die.

When it comes to mother's social or occupational opportunities the developmentally disabled child is more likely to have a neutral or positive effect than a negative effect (Table V-C, "Perceived Effect"). At the same time, counseling or respite care may be necessary for: the two-fifths who perceive their involvement in outside social activities to have been curtailed (Item 3), and the one-seventh who perceive home entertaining and geographic mobility to have been adversely affected (Items 5 and 6).

Age of Child. While age of child does not seem to be associated with mothers' feelings about their children, the older the child, the more likely mothers are to report a curtailment of social and occupational opportunities.

Type of Disability. The more severe the disability, the more likely mothers are to admit having negative feelings about their children. That is, mothers with children having severe and profound retardation, cerebral palsy, or autism are more likely to wish they could go out more, feel "trapped" at home, and have wished their child would die. They are also more likely to perceive their social and occupational opportunities as having been restricted.

Family Income. In general, the higher the family income the more likely mothers are to express negative feelings and perceive negative effects.

2. Effects on Fathers and Marriages

As was the case for mothers, the effect on the majority of fathers is perceived as beneficial (Table V-D). In general, husbands are not perceived as being affected as greatly as mothers.

3. Time and Planning

In general, families seem to handle the developmental needs of their children very well (Table V-E). Over two-thirds spend between an hour to one-half of their available time with their children. Less than ten percent fall at either extreme, either spending only a few minutes a day or having little time to do anything else.

Overwhelmingly, mothers accept the major responsibility for finding out what is available for their children and deciding among alternatives (Table V-F). In terms of finding out about what is available mothers are equally likely to act on their own or in conjunction with their husbands. However in deciding on an alternative, that is in acting upon information, both husband and wife are much more likely to be involved. Mothers are more likely to be the information gatherers, with husbands retaining decision-making power. In only a very small proportion of families (2% or less) do fathers act on their own or do grandmothers or other kin become involved in obtaining information or decision-making.

Table V-C

Effect of Developmentally Disabled Child on Self
(Rank ordered by agreement and perceived good effect.)

Feelings	Agree	Uncertain	Disagree	
1. I consider my time with this child to be well spent.	84.5%	10.7	4.7	N = 317
2. Having a developmentally disabled child has made me a better person.	63.3%	23.5	13.2	N = 319
3. I feel uncomfortable leaving my developmentally disabled child at home when I go out.	30.7%	6.1	63.2	N = 313
4. I wish I could go out more without this child.	21.0%	9.1	69.9	N = 309
5. I feel "trapped" at home because of my developmentally disabled child.	14.7%	13.8	71.4	N = 312
6. Sometimes I've become so frustrated by problems caused by the developmental disability that I've wished our child would die.	11.5%	3.8	84.7	N = 314
Perceived Effect	**Good**	**No Effect**	**Bad**	
1. Learning new skills.	48.1%	45.2	6.6	N = 314
2. Religious involvement.	34.1%	59.8	6.1	N = 311
3. Involvement in social activities outside your home.	29.2%	50.0	20.9	N = 312
4. Political involvement.	18.3%	77.8	3.9	N = 311
5. Entertaining people in your home.	12.6%	73.5	13.9	N = 309
6. Moving the family for new job opportunities.	5.3%	81.1	13.6	N = 301
Making a success of your career	13.3%	74.1	12.7	N = 158

Table V-D

Effect of Developmentally Disabled Child
on Husband and Marriage
(Rank ordered by agreement and perceived good effect;
questions answered only by married respondents.)

Feelings	Agree	Uncertain	Disagree	
1. I'm satisfied with the amount of time I'm able to spend alone with my husband.	64.3%	11.8	23.9	N = 272
2. Having a developmentally disabled child has made my husband a better person.	52.6%	29.2	18.3	N = 274
3. Having a developmentally disabled child has brought my husband and me closer together.	51.3%	23.6	25.0	N = 275
4. Sometimes my husband has become so frustrated by problems caused by the developmental disability that he's wished our child would die.	3.7%	11.7	84.7	N = 273
Perceived Effect	**Good**	**No Effect**	**Bad**	
1. Your marriage.	37.6%	49.1	13.3	N = 271
2. Your husband's making a success of his career.	7.4%	88.1	4.5	N = 270

Table V-E

In order to help a developmentally disabled child learn as much as possible, adults may spend a lot of time working with him/her outside school. For example, this time may include things like physical exercise, simple tasks like tying shoelaces, reading practice, helping with homework, talking to your child, or playing games. How much of <u>your</u> <u>time</u> on a week day is regularly spent in such activities with your child?	
No time; child does not live at home.	12.4%
Only a few minutes a day.	9.2
About an hour a day, more or less.	33.3
About half the time my child is at home.	36.2
I do not seem to have time to do much else when my child is at home.	8.9
	N = 315

Table V-F

In making plans for children, usually parents go through two steps:
(A) finding out about what is available; and
(B) deciding which plan to follow.
Think about how plans are made for your developmentally disabled child.

(A) Who find(s) out about what is available?

Self	46.9%
Husband	2.0
Both spouses	48.8
Self and mother	1.3
Self and friend or relative	1.0
	N = 303

(B) Who decide(s) which alternative to choose?

Self	14.1%
Husband	1.6
Both spouses	81.7
Self and mother	1.6
Self and friend or relative	1.0
	N = 306

C. SIGNIFICANT OTHERS

The isolation of the nuclear family (husband, wife and dependent children) and the burden of responsibility for a developmentally disabled child can be lessened if support networks are available. Natural support networks include grandparents, siblings, other relatives, and friends and neighbors. Professionals augment these natural networks.

1. Domestic Support

Regular help with activities that stimulate development is most likely to be provided by other members of the nuclear family (Table V-G). In a majority of the families siblings or husbands are reported as helping regularly. Grandparents are available on a regular basis in about one-quarter of the families. Friends and professionals are least often available, but even so they help about one family in six on a regular basis.

For those families where one or more grandparents are still living, the grandparents appear to accept the child's disability and agree with the way parents are handling the situation (Table V-H). Grandparents put their feelings into practice through enjoyment of photographs, remembering children's birthdays and offering child care when appropriate (Table V-I).

Parents are much more likely to get help with their children's social needs (Table V-J, items 1-5) than with their routine physical care or household maintenance (items 6 and 7). Approximately two-thirds of the families receive help at home with comforting the child, building character, social visits and discipline. Tangible help with play, instruction, care of body and housekeeping duties occur less frequently. Help with housekeeping duties, the one area which does not necessarily involve contact with the child is the area where help at home is least utilized.

Age of Child. The younger the child the more likely help was to be received from significant others and the more likely it was to be utilized for a variety of needs within the home. An exception occurred with help from siblings which was more likely to occur for children of primary or secondary school-age. Since both older and younger siblings are able to provide help, it is most likely that they are present at home and able to do so for children in these intermediate age groups. Younger siblings of preschoolers would be too young to provide much help and older siblings of those in the transitional age group would be likely to have already left home.

Type of Disability was not associated with help received from natural support groups. Professionals, however, were more likely to provide regular help outside the school environment for children with severe and profound retardation and cerebral palsy (for about one-quarter of the children compared to about one-tenth for the others). The findings suggest that this type of professional help is associated with physical disabilities. Grandparents, on the other hand, were more likely to deny the child's disability and to offer support to parents of children with mild retardation. Parents of children with cerebral palsy were most likely to get help at home with a variety of needs; while parents of the mildly retarded were least likely.

Family Income. Husbands from high income families were more likely to spend extra time with the children on a regular basis. Grandparents and other relatives were more likely to spend extra time with children on a regular basis in low income families. The amount of family income did not affect whether or not regular help was received from siblings, friends and professionals. Grandparents offered more emotional support in high income families. They were more likely to approve parents' handling of the situation, to accept the children's disabilities, to oppose residential placement, to have as much contact as if the children were normal, to enjoy having photographs, to remember the children's birthdays, and to offer care for the children for short periods. On the other hand, it was in the lower income families that grandparents were more likely to be reported as wanting the children to live with them if something happened to the parents.

2. Confidants and Consultants

Significant others were utilized as sources of emotional support, as confidants (see Table V-K) and as sources of information, as consultants (see Table V-L).

As might be expected, members of primary groups are frequently confided in when there are worries about the developmentally disabled child (husbands 88.8%, and friends and relatives 41.9%, being confided in often). What is perhaps more interesting is that social service professionals also seem to be operating in this capacity traditionally associated with members of the primary group of extended family (48.5% often confide in social service professionals). Conversely respondents are least likely to confide in a rabbi, minister or priest, or to keep their worries to themselves.

When advice is sought, as might be expected, health service and educational professionals are those most likely to be talked to as "expert" sources of information (4/5 would talk to their child's doctor, or teacher or principal). Again, what is perhaps more interesting is that parents are next most likely to talk to other family members or friends, choosing these primary group members as consultants ahead of organizations specifically concerned with their child's disability or other professionals such as social workers or psychologists. Least likely to be consulted for advice are librarians or staff members of a State governmental office. Underutilization of these information sources could result from either a lack of awareness of their expertise or availability, or from negative evaluations of the value to be gained from contacting these sources.

3. Self-Help Mutual Aid

Few parents have made their child's developmental disability the focal point of their friendships network (Table V-M). Only 3% report most or all of their closest friends also having children who are developmentally disabled. It may be of concern that twenty-four of the parents in our survey (8% of the total sample) reported not having any close friends. The effects of a developmental disability on families may well be augmented in cases of social isolation.

Parents come together to form mutual aid groups primarily through naturally

occurring social networks rather than through the direct intervention of professionals (Table V-N). By far the most important source of contact is the child's school (82%). The next most important sources are by regular contact with friends or relatives or by chance, as part of the routines of daily living (45% and 37%, respectively). A smaller number make contacts through voluntary organizations (26%), through professionals (20%) and through religious leaders (6%).

Age of Child is not associated with opportunities for contacting other parents of developmentally disabled children (except for the obvious case of opportunities through the child's school).

Type of Disability. In general, the more severe the disability, the more likely contact is to be made with other parents through all available channels. Parents of children with mild retardation are notably lower in terms of making such contacts; parents of children with autism are notably higher. Parents of children with more definitive diagnoses (cerebral palsy, autism, and epilpsy) are more likely to meet other parents of developmentally disabled children through voluntary organizations than are parents of children with mental retardation.

Family Income. In general, the higher the income the more likely parents are to make contact through all available channels.

Parents' Comments on Relationships with Family and Friends
As a Result of Having a Developmentally Disabled Child

We have been most fortunate in having kind-hearted, sympathetic and understanding friends and relatives. They were educated along with us and have not been made to feel uneasy or uncomfortable in any situation or surroundings. We have also received a great deal of encouragement from them. (#091)

Friends are concerned and sympathetic but do not know quite how to respond to child. Some even a little embarrassed about asking about the child. Family has been a great help and all seem genuinely to love and care about this child. (#318)

Very few friends and most of family were unable to accept my child's severe retardation. (#773)

Our friends and family have accepted our son very well. I think we have all become considerate and thoughtful to any handicapped person. Most of us had no contact with handicapped people before. We have, also, become very active in my son's school and our community. Out of this, we have many new friends with handicapped children. (#321)

I find most relatives overreact to the disability and are afraid to be left alone with the child. Also they either expect too much from them or treat them like babies and hand out advice without having any idea of what living with or raising a disabled child is like. Friends, on the other hand, respect the way I treat my child and treat her the same always asking me to bring her along to play with their child or children although children of the same age seldom have the patience to play with her and would rather be with their own friends. (#382)

Many friendships ceased to exist. Some people were afraid their children would "catch it", too. Some of our "normal" child's friends couldn't visit at our home because of our d.d. child. (#258)

The attitude changes of all those involved by knowing a retarded child are remarkable. Most people I have met and become good friends with and do not have retarded children seem to grow in their awareness of the value of life. They tend to stop and think of the importance of time and slow down in their rat race of living to appreciate what they have. (#774)

We are more or less by ourselves. We can't go with him too many places. Not too many people are willing or able to babysit with him. And we couldn't afford it too much anyhow. His brother and sister don't want much anything to do with him. They may babysit with him when it's really necessary. We don't have too many friends or relatives come to visit us.

Table V-G

Is there another person who regularly spends extra time outside school with your child on such activities? (Rank ordered by frequency help given.)	
	% Yes (N = 317)
1. Child's brothers or sisters	57.7%
2. Your husband	56.0%
3. Child's grandparent or other relative	24.0%
4. A friend or neighbor	15.8%
5. A professional (for example, a physical therapist, a tutor)	13.9%

Table V-H

Sometimes grandparents give opinions about how parents are raising their children. How do you think your child's grandparents feel about the developmental disability? (Question answered only if any of child's grandparents still living; rank ordered by agreement.)

	Strongly Agree	Somewhat Agree	Disagree	
1. They think I am handling the situation well.	70.4%	27.0	2.6	N = 274
2. If something happened to us, at least one of them would want the child to live with them.	43.8%	23.6	32.7	N = 272
3. They think my child should be in a residential school.	16.4%	22.1	61.4	N = 262
4. They do not see anything wrong with my child.	11.9%	24.9	63.2	N = 261
5. I think that we do not have as much contact with them as we would if the child were normal.	6.0%	11.2	82.7	N = 266

Table V-I

Involvement of Grandparents of Developmentally Disabled Child. (Rank ordered by type of involvement.)

	Always	Sometimes	Hardly Ever	
1. Enjoyed having and looking at photographs of the child?	84.6%	13.2	2.2	N = 272
2. Remembered the child's birthday?	86.2%	10.4	3.3	N = 269
3. Offered to care for the child for short periods when appropriate?	47.6%	32.7	19.6	N = 275

Table V-J

Do you get help at home in caring for the needs of your developmentally disabled child with any of the following? (Rank ordered by frequency of type of help received.)	
	% Yes (N = 322)
1. Concern and comfort (for example, help with calming child when upset or hurt, hugs and kisses child, giving special attention when sick.	68.6%
2. Building character (for example, teaching manners, reminding child of how to treat others, expecting child to eat properly.	68.6%
3. Social visits (for example, taking child to visit friends or relatives, taking on errands, taking to church.	68.3%
4. Discipline (for example, correcting child for misbehaving, getting child to bed on time, punishing child if necessary).	66.1%
5. Play/instruction (for example, help with teaching child sports and games, schoolwork or therapy, taking on walks).	59.6%
6. Care of body (for example, help with bathing, feeding, toileting, putting to bed at night).	47.2%
7. Housekeeping duties (for example, cleaning up after child, doing child's laundry).	37.0%

Table 7-K

Confidants (sources of emotional support).
When you are worried about something concerning your developmentally disabled child, how often do you confide in each of the following? (rank ordered by frequency as source of emotional support)

	Often	Sometimes	Hardly Ever	
1. My husband	88.8%	9.8	1.4	N=276
2. Social Service professionals (school personnel, social worker, etc.)	48.5%	32.6	18.9	N=307
3. A friend or relative	41.9%	32.1	26.0	N=308
4. A doctor or other medical professional	39.0%	34.7	26.3	N=308
5. Other parents with developmentally disabled children	19.5%	30.3	50.2	N=297
6. No one; I keep it to myself	7.5%	12.2	80.3	N=295
7. A rabbi, minister or priest	4.7%	12.0	83.3	N=300

Table 7-L

Consultants (sources of information).
Parents often react differently to advice depending upon who gives it. If you had a serious decision to make about your developmentally disabled child, would you talk to any of the following? (rank ordered by frequency as source of information)

	Would	Depends	Would not	
1. Child's doctor	81.8%	12.0	6.1	N=308
2. Child's teacher or principal	79.3%	12.9	7.8	N=309
3. Other family members or friends	67.7%	15.7	16.6	N=300
4. An organization specifically concerned with your child's disability	63.8%	25.2	11.0	N=309
5. Other professional (such as a social worker or psychologist)	59.4%	27.1	13.5	N=303
6. Other parents with developmentally disabled children	40.4%	33.7	25.9	N=297
7. A priest, minister, or rabbi	24.5%	24.2	51.4	N=298
8. Someone in a State governmental office	14.8%	26.6	58.6	N=297
9. A librarian	5.1%	8.5	86.4	N=294

Table V-M

Think of your closest friends. Do they have children who are developmentally disabled?	
All do	1.0%
Most do	1.7
Half do	5.0
Most do not	30.5
None do	61.7
	N = 298
(Number not having any close friends = 24)	

Table V-N

Have you met other parents of developmentally disabled children in any of the following ways?	
	% Yes (N = 329)
Through child's school, including parent group meetings.	82.1%
Through friends or relatives.	44.7%
By chance (for example, while shopping, finding a parent's name in a newspaper, at work).	37.1%
Through voluntary organizations (for example, Easter Seals, NARC).	25.8%
Through a professional (for example, social worker, nurse, doctor).	19.5%
Through a priest, minister, rabbi.	6.4%

Table V-O

Would you like to know more people whose children are developmentally disabled?	
Yes	59.4%
No	18.2
It doesn't matter to me	22.4
	N = 303

VI.
DIAGNOSIS AND ASSESSMENT

A. RECOGNITION BY FAMILY

Most parents are unprepared for the birth of a child with a developmental disability (Table VI-A). Approximately two-thirds have no prior familiarity with developmental disabilities. Although one-third had known others with disabilities, only one-fifth knew about community resources- and only one-twelfth had been involved in the field of developmental disabilities. There is some evidence of a trend towards an increase in general public awareness; 56% of parents of preschoolers had no prior familiarity with developmental disabilities compared to 72% of parents of 18 to 21 year olds.

The stage at which a developmental disability is recongized can be quite variable (Table VI-B). In 70% of the cases recognition of the disability occurred before the children's second birthdays. For the remaining 30% recognition was more likely to occur in the preschool years but for some did not occur until at least junior high school. Evidence towards an increased public awareness is supported by the finding that the younger the child, the more likely parents recognized the disability before the children's second birthdays. As would be expected, the more severe the disability, the earlier it was recognized. For over one-half of the children with mild mental retardation or epilepsy their disabilities were not recognized until after their second birthdays.

Recognition of a disability is not a simple process. For our sample it was about equally likely that the disability would be reocgnized by the family as it would be recognized by a professional (Table VI-C). That is, it is equally likely that parents find themselves in the position of convincing professionals as it is that professionals are in the position of informing parents. Whether the developmental disability is recognized by family members or professionals is not associated with the child's age, type of disability, or family income. It does seem to be the case that public awareness has increased and not just professionals' awareness.

Developmental disabilities are recognized by parents through a number of symptoms (Table VI-D). Recognition of the disability occurred most frequently due to delays in language development(52% of the cases) and poor motor control (43%).

Age of Child was not systematically associated with the symptom by which parents recognized the disability.

Type of Disability. Parents of children with moderate or severe and profound retardation were most likely to recognize immediately at birth that their children had developmental disabilities (29% and 24%, respectively). Parents of children with cerebral palsy or epilepsy were more likely to recognize the disabilities by the presence of physical symptoms after birth. Parents of cerebral palsied children recognized the disability by their children's poor motor control (85%) and their worrisome general physical condition (44%). Children with epilepsy were usually recognized by the presence of seizures (85%). Inappropriate social responses were the most frequent precipitating indicators of disability for children with cerebral palsy (44%), autism (40%) and severe and profound retardation (38%). As would be expected parents of children with mild mental retardation

were most likely never to have suspected anything but were informed by others that things "were not quite right" (46%).

Family Income was not systematically associated with the symptoms by which parents recognized the disability. The only exception was that the higher the families' income the less likely parents were to have never suspected their children's disabilities. This may be explained by the fact that higher incomes are usually associated with more years of education, and more highly educated persons might be more likely to be sensitive to developmental milestones and delays.

Table VI-A

Before you knew that your child was developmentally disabled:	
	% Yes (N = 328)
Did you know others who had children with such disabilities?	32.3%
Did you know about community resources available for children with disabilities?	20.4%
Were you involved in the field of developmental disabilities through volunteer work, college courses, or employment?	7.9%
Were you unfamiliar with both the reality of developmental disabilities and the possibilities of coping with them?	62.8%

Table VI-B

The stage at which parents first notice that their child has a problem varies greatly from family to family. At which of the following stages of development did you first realize that your child had a disability?	
During pregnancy or at birth	25.5%
During the first two years	45.1
During the third or fourth year	13.2
At kindergarten age	9.5
First grade to sixth grade	6.1
Seventh grade and upwards	0.6
	N = 326

Table VI-C

Who first recognized the developmental disability?	
A doctor (for example, obstetrician, pediatrician, family practitioner)	42.1%
I and/or my husband	40.5
A teacher or school psychologist	11.5
A friend or relative	3.7
A public health nurse, social worker, or outreach worker	2.2
	N = 321

Table VI-D

How did you recognize the developmental disability?
(Rank ordered by visibility of delay.)

	% Yes (N = 319)
1. Failure of language to develop normally.	52.5%
2. Poor motor control (for example, the child did not move arms and/or legs properly; did not crawl "at the right time"; did not seem to focus his/her eyes on anything).	43.1%
3. I never suspected anything but somebody else kept pointing out things that "were not quite right."	30.3%
4. Inappropriate social responses (for example, she/he did not seem to recognize me or my husband; did not begin to smile when I thought she/he should).	27.9%
5. Worrisome general physical condition (for example, sucking problem; she/he did not seem to be gaining weight properly; seemed to get sick too often; unusual sleeping pattern).	24.8%
6. Recognized immediately at birth from appearance.	20.9%
7. Seizures (convulsions, spells or fits).	18.8%
8. Inappropriate or inconsistent display of emotions (for example, self-destructive activity, unconnected angry outbursts; lack of warmth and loving behavior).	16.6%

B. INITIAL MEDICAL CONTACT

The initial medical or professional contact that parents of developmentally disabled children make is the first step in the service cycle that will continue throughout the child's lifetime. If the diagnosis is relatively straightforward, its implications adequately explained, and appropriate referrals made, then needed services will be obtained more quickly and in a supportive manner for the child's development. On the other hand, if professionals are ambivalent about making a diagnosis, explain its implications in a negative fashion, and make inappropriate referrals, then there will be a delay in obtaining services with corresponding lost opportunities for fostering development.

1. Initiating Contact

When mothers first realized that their children had a developmental disability they were more likely to talk about it to a doctor than to any other family member, friend, or professional (Table VI-E). A majority talked about the disability with physicians (87%), husbands (80%) and friends or relatives (55%). A much smaller number talked to school personnel or other professionals (24%) or to religious leaders (10%). Almost one-half immediately acted upon their suspicions to have a doctor examine their children (Table VI-F). For approximately another one-quarter of the respondents it was not necessary to initiate contact because the disability was diagnosed at birth. Finally, nearly one-quarter delayed having a medical consultation, 15% initiated it themselves and for 11% professionals arranged the medical consultation.

Age of Child. The younger the children the more likely parents were to have talked about the disability right at the start to doctors and friends or relatives. The older the children the more likely parents were to have talked to teachers or school psychologists when they first realized their children had a disability. It seems that parents of younger children are more likely to think of the medical and social ramifications of the disability whereas parents of older children placed more emphasis on educational implications. The younger the children the more likely parents were to have immediately sought medical consultation when they suspected a developmental disability.

Type of Disability. Visibility of the disability seems to make it more likely that parents will consult physicians or friends and relatives when they first realize their children have a disability. It was least likely that parents of mildly retarded children would have done so. On the other hand teachers or school psychologists were most likely to have been contacted by parents of mildly retarded children. Parents of children with autism or severe and profound retardation were most likely to have contacted religious leaders. Type of disability was not related to the frequency with which mothers would talk to their husbands or other professionals. The more severe the retardation the more likely parents were to obtain a medical examination immediately. Parents of children with cerebral palsy, autism, or epilepsy were even more likely to arrange for an immediate medical examination than were parents of severely and profoundly retarded children.

Family Income. The higher the family income the more likely mothers were to talk to doctors, husbands and friends and relatives. Conversely, the lower the family income the more likely mothers were to talk to teachers, school psychologists, or other professionals. Consistent with the tendency for higher income families to talk about their children's disabilities these higher income families were more likely to arrange immediately for a medical examination.

2. First Medical Visit

A majority of mothers were alone when they first talked with their doctors about their children's disabilities (Table VI-G). A substantial minority (38%) were accompanied by their husbands. Most of their doctors provided clear explanations on the initial visit (Table VI-H) with or without parents needing to ask further questions (46% and 37%, respectively). Where medical terminology was not explained on the first visit this was more often due to the parents' reactions (12%) than because the doctor seemed too busy (6%).

Approximately two-thirds of the parents reported that their doctor's manner was supportive when their children's diagnoses were first explained (Table VI-I). One-third or less of the parents perceived the doctors' manners to be pessimistic, unsure, evasive or harsh. Few differences were reported by age of child or type of disability: more parents of older children reported doctor's manner as sympathetic; more parents of younger children reported doctor's manner as matter-of-fact and harsh; more parents of autistic children reported doctor's manner as unsure. After the first medical visit was completed, most parents felt the doctor provided enough time to explain the developmental disability adequately (Table VI-J). Still, slightly over one-quarter felt not enough time had been taken.

3. Referrals and Recommendations

Less than one-half of the first doctors provided information concerning referrals or family support (Table VI-K). Doctors are most likely to provide diagnoses and make referrals to other medical specialists--45% to 47%. They are next most likely to suggest a prognosis (38%). If support systems are initiated by the doctor, it is most likely to take the form of talking to both parents together (32%). Referrals, made 25% or less of the time, are most likely to be through more formal channels, that is, to community services, organizations or institutions. Referrals and recommendations are only infrequently made to disability self-help groups, to particular programs for the disabled, or for explaining the disability to others.

Table VI-E

When you first realized that your child had a disability did you talk about it to: (Rank ordered by frequency of contact)		% Yes (N = 322)
1.	A doctor (for example, obstetrician, pediatrician, family practitioner)?	87.0%
2.	Your husband (the child's father)?	80.1%
3.	A friend or relative?	55.3%
4.	A teacher or school psychologist?	24.5%
5.	Other professional (for example, public health nurse, social worker, outreach worker)?	24.5%
6.	Minister, priest, or rabbi?	9.6%

Table VI-F

When did you first ask a doctor to examine your child to find out whether there was a developmental disability?	
Immediately when I began to suspect.	48.1%
Somewhat later; to give myself time to think about it and be sure.	11.5
Before she/he started school, since I figured at that point something would have to be done.	3.2
I never did; a professional (teacher, counselor, psychologist) arranged it.	10.6
It was not necessary; the disability was diagnosed at birth.	26.6
	N = 312

Table VI-G

When you first talked with a doctor about your child's disability, were you:	
Alone?	53.5%
With your husband (the child's father)?	38.1
With a friend or relative?	6.4
With a professional (for example, social worker, patient advocate)?	1.9
	N = 312

Table VI-H

When the doctor told you what she/he thought the developmental disability was and used medical words that you did not understand, what did you do?	
I asked questions and got them better explained.	45.9%
I let it pass, since the doctor seemed too busy to take time to explain them.	5.6
I was reluctant or too shocked to ask further questions at the time.	11.9
It did not happen: the explanation was clear to me.	36.6
	N=303

Table 7I-I

Doctor's manner when child's diagnosis first explained to parent.	% agree
Supportive manner	
Patient	77.4%
Matter-of-fact	72.2%
Sympathetic	64.9%
Broke the news gently	60.9%
Negative manner	
Pessimistic	33.5%
Unsure	30.2%
Evasive; nervous	20.6%
Harsh	11.7%

Table 7I-J

About how long would you say this first doctor spent with you, after telling you about the developmental disability?	
No time at all.	12.9%
Not enough time to answer all my questions.	15.9
Not enough time then to answer all my questions but made another appointment.	9.7
Enough time to explain it adequately.	61.5
	N=309

Table VI-K

Did the first doctor you talked to about the developmental disability do any of the following? (rank ordered by frequency with which help provided).	% yes
1. Give a specific label for your child's developmental disability.	46.8%
2. Refer you to a specialist.	45.5%
3. Suggest what the future would look like for your child.	37.9%
4. Ask to talk with you and your husband (the child's father) together.	31.8%
5. Tell you about services available in the community.	25.8%
6. Refer you to organizations concerned with your child's disability.	21.7%
7. Suggest institutionalizing your child, either immediately or in the future.	18.8%
8. Suggest you meet other parents of children with developmental disabilities.	11.1%
9. Suggest a particular program for your child (for example, early intervention, Montessori, Dolman-Delacato, orthogenic).	11.1%
10. Tell you how to explain the disability to family, friends, and others.	8.3%

C. SUBSEQUENT CONTACTS

Subsequent medical or professional consultations are frequently necessary to confirm the diagnoses of a developmental disability. Diagnoses and assessments of children suspected of having developmental disabilities often require the cooperation of professionals from different disciplines. Uncertainty about the first diagnosis may be explained by either the medical professionals or parents. Professionals are reluctant to label a delay as a disability until the child is old enough for it to be obvious that the delay seems permanent. The rates of physical, cognitive, social, emotional and language development can be quite uneven for normal children. Parents may become aware of and concerned about delays which are still within the normal developmental range. Parents may become frustrated when professionals are ambivalent about confirming or denying the significance of the delays. On the other hand, parents' love for an individual child may blind them to disabilities which are obvious to professionals. In either case where there is a lack of consensus between professionals and parents, other opinions will be recommended or sought. In the sample, 35% of the parents had changed their children's doctors because of dissatisfaction with the care provided. Parents were more likely to change doctors if the children's disabilities were severe or their family incomes were higher.

1. Types of Medical Professionals Contacted

The first medical professional to examine a child for a developmental disability is likely to be the regular physician for children in that age range (Table VI-L). Four-fifths of the children in our sample were first examined by a pediatrician or a family practitioner. In contrast, parents tend to have subsequent medical examinations performed much more frequently by specialists (Table VI-M). Most frequent additional contacts are with special clinics, diagnostic or genetic centers (59%) and with neurologists (42%). Pediatricians, however, are almost as highly utilized for second or additional opinions (41%) as for the first examination, whereas general practitioners are not.

Age of Child is not systematically associated with type of medical professionals contacted for subsequent examinations.

Type of Disability. There was no association between the type of disability and whether additional examinations were conducted at a special clinic or by a pediatrician, audiologist, family practitioner or obstetrician. The opinion of a neurologist was more likely to be sought for children with cerebral palsy, autism or epilepsy (by approximately 70% of parents) than if the children were severely and profoundly retarded (50%) or if the children were mildly or moderately retarded (approximately 30%). The opinion of a psychiatrist was most frequently sought in cases of ambiguity: for children where diagnosis is controversial (by 64% for children with autism), children where manifestation of symptoms is unpredictable (by 33% for children with epilepsy), and for children where some functional skills are likely to be within the normal range (by 25% for children with mild retardation).

Subsequent contacts with psychiatrists occurred for only about one-eighth of children with moderate, severe or profound retardation and cerebral palsy.

2. Source and Outcome of Referrals

The most common source of referral to another doctor or clinic (Table VI-N) was the doctor initially seen (47%) with self-referral closely following (36%). The reliability of the initial medical diagnoses was established with subsequent contacts with one or more additional doctors for 75% of parents making subsequent contacts (Table VI-O).

Age of Child was not associated with the reliability of the initial diagnosis as established by subsequent contacts.

Type of Disability. The reliability of the initial diagnosis was highest for children with epilepsy (96%) and lowest for children with autism (20%). The diagnoses were reliable for 75% of the remaining disability categories.

Family Income was not associated with the reliability of the initial diagnosis as established by subsequent contacts.

3. Scope of Prognosis

More than two-thirds of the parents found at least one doctor gave them a notion of what their children's futures held (Table VI-P). Greater than one-third of the doctors expressed uncertainty or ignorance concerning children's disabilities and their effects (39%), offered copies of lab reports or other medical findings (35%), and suggested that parents should institutionalize their children (34%).

Age of Child. Only one of the four aspects of prognosis was associated with age of child. The younger the child the more likely doctors were to have expressed uncertainty or ignorance concerning the disability and its effects. Approximately one-half of parents of preschool and primary age children, 0 to 12 years, reported doctors' expressing uncertainty or ignorance compared to approximately one-quarter of parents of older children. This difference seems likely due to the increased use of medical specialists in the diagnosis and treatment of developmentally disabled children. As doctors are more likely to make referrals, they can be more honest about their own limitations.

Type of Disability. Although not statistically significant, parents of children with autism were the most likely to report doctors' expressing uncertainty or ignorance (64%) and offering copies of reports or findings (54%). There was an association between type of disability and doctors' willingness to provide or project a plausible future. Projections were more likely to be for disabilities where the future is more certain; moderate mental retardation (70%); severe and profound retardation (83%); cerebral palsy (74%); and epilepsy (63%). Where the future is less certain doctors were less likely to make projections: autism (54%) and mild mental retardation (51%). Doctors' recommendations to institutionalize were also related to type of disability. At the extremes, only 10% of parents with mildly retarded children reported institutionalization ever having been recommended

by a doctor compared to 69% of parents of severely and profoundly retarded children.

Family Income. Doctors were most likely to express uncertainty or ignorance concerning disabilities or offer lab reports or other findings to high income families.

4. Reference Materials

Nearly three-quarters of parents (Table VI-Q) read about their children's disabilities in newspaper or magazine articles. About two-fifths located reading materials through friends and relatives, through libraries or organizations, or through suggestions from medical or educational professionals.

Age of Child. Parents of preschool children were less likely to have seen articles in newspapers or magazines but friends and relatives were more likely to provide reading materials to parents of young children.

Type of Disability. Parents of mildly retarded children were much less likely to obtain reading materials by chance, through friends and relatives or through libraries and organizations.

Family Income. High income families were more likely to obtain reading materials from all sources.

Table VI-L

The first doctor who examined your child for a developmental disability was: (Ordered by frequency of assessment)		
1.	Pediatrician	52.4%
2.	Family practitioner (G.P.)	28.3
3.	Neurologist	7.7
4.	Obstetrician	6.3
5.	Psychiatrist	2.8
6.	Audiologist	2.4
		N = 286

Table VI-M

Many people want the opinion of another doctor. Have you taken your child to any of the following for a second or additional examination? (Rank ordered by frequency of contact)		
		% Yes (N = 323)
1.	A special clinic, diagnostic, or genetic center	58.8%
2.	Neurologist	42.4%
3.	Pediatrician	40.6%
4.	Audiologist	26.3%
5.	Psychiatrist	19.2%
6.	Family practitioner (G.P.)	18.3%
7.	Obstetrician	4.0%

Table VI-N

Whose idea was it to take your child to another doctor or clinic? (Ordered by frequency of referral)	
1. My first doctor	47.4%
2. I and/or my husband	36.2
3. Another professional (for example, social worker, teacher, public health nurse).	13.4
4. A friend or relative	3.0
	N = 268

Table VI-O

Did the doctor(s) you saw later agree with the first doctor? (Ordered by frequency of agreement)	
1. Saw more than one and all agreed.	48.0%
2. Only saw one other who agreed with the first.	27.7
3. Saw more than one and some disagreed.	20.3
4. Only saw one other who disagreed with the first.	3.9
	N = 256

Table VI-P

In all your experiences with doctors concerning your developmentally disabled child, have any of these doctors ever: (Ranked by frequency of behavior)	% Yes (N = 321)
1. Given you an idea of what they think the future holds for your child?	67.6%
2. Expressed uncertainty or ignorance concerning your child's disability and its effects?	38.6%
3. Offered you copies of lab reports or other medical findings?	35.2%
4. Suggested that you should institutionalize your child?	34.0%

Table VI-Q

Did you find things to read about your child's disability in any of the following ways? (Rank ordered by frequency of source of information.)	
	% Yes (N = 324)
1. I would sometimes happen to see articles in the paper or in magazines.	71.3%
2. Friends and relatives would sometimes show me things to read.	41.7%
3. I went to the library and/or an organization.	41.4%
4. Professionals (such as doctors or teachers) would suggest things to read.	39.5%

VII.
COMMUNITY RESOURCES

A. HEALTH CARE AND SOCIAL SERVICE DELIVERY

1. Health Care Delivery

Developmentally disabled children have the same health care needs as do all children. In this respect it perhaps should be of concern that 10% of the parents do not anticipate ever having any contacts with either a pediatrician or a dentist. Developmentally disabled children often have additional health care needs. Neurologists, ophthalmologists, audiologists, and ear, nose and throat specialists are contacted by approximately 3/5 of the parents; psychiatrists, orthopedists by approximately 1/3; obstetricians, orthodontists, oral surgeons, cardiologists and plastic surgeons by 1/4 or less. (See Table VII-A).

Frequency of contact is influenced by demographic factors.

Age of Child

One would expect contact to increase as children grow older. This is the case for contact with: family doctors, obstetricians, ear, nose and throat specialists, opthalmologists, dentists, oral surgeons, neurologists, and psychiatrists.

On the other hand, parents of preschool children report the most contact with pediatricians, orthopedists, and audiologists. This may reflect the availability of early intervention programs and resultant increase in parent awareness.

Supporting the argument that both availability and awareness influence use of health care services is the finding that parents of primary and secondary-age children are more likely to contact orthodontists than are parents of either preschoolers or 19 to 21-year-olds. Preschoolers would be less likely to need the service; parents of the oldest group the least likely to have been aware of the service and its benefits.

Type of Disability

In general, the more severe the retardation, the more likely parents were to have contacted medical professionals. The two exceptions are that parents of the mildly retarded were more likely to have contact with family doctors and psychiatrists.

Parents of children with autism were most likely to have contact with audiologists, ear, nose and throat specialists, and psychiatrists. The difference for the latter was quite pronounced with 90% having contact with psychiatrists. The next most frequent contact with psychiatrists by type of disability occurred for parents of mildly retarded and epilepsy (44% in each case). On the other hand, no parent of an autistic child had or expected to have contact with a plastic surgeon.

Parents of children with cerebral palsy were the most likely to have contact with ophthalmologists, orthopedists, and neurologists (87%, 84% and 94% respectively). There are no systematic patterns for parents of children with epilepsy.

Family Income

Higher income enables families to purchase more services. On the other hand, sliding fee scales make services available to lower income families; and risk factors associated with low income (such as lower birthweight, poor nutrition) may increase the need for medical services.

The higher the income, the more likely families were to contact: pediatricians, dentists, neurologists, ophthalmologists, ear, nose and throat specialists, orthopedists, orthodontists, and plastic surgeons.

Conversely, lower income families were more likely to contact: family doctors (G.P.'s), psychiatrists, and cardiologists.

Income did not exert a systematic effect on the frequency with which families consulted: audiologists, obstetricians, or oral surgeons.

2. Social Service Delivery

A developmental disability may create social service needs for both children and their families. A majority of families have had contact with speech therapists, social workers, and physical therapists. Between 1/4 and 1/2 of the families have had contact with clinical psychologists, public health nurses, occupational therapists, and recreational therapists. Less than 1/4 of the families have had contact with family, group or individual therapists, genetic counselors, vocational counselors, nutritionists, house or foster parents, and professional homemakers. (See Table VII-B.)

Age of Child

Needs for social services at this time seem to be much more stable over the life cycle than was the case for health care services. Age of child was not related to families' contact with: clinical psychologists, public health nurses, occupational therapists, recreational therapists, nutritionists, and professional homemakers. Stability of contact could be due to relatively unchanging needs over the life cycle of a developmentally disabled child, lack of awareness of how these professionals may provide assistance, and/or lack of availability.

Planning for vocational and residential options does increase the frequency of contact with some professionals over the child's life cycle. There are more needs and services to be coordinated in adolescence and early adulthood. Parents of older children have had more contact with: social workers, vocational counselors, and house or foster parents. As can be seen from Table VII-B, the increased utilization of these professionals is projected for vocational counselors only.

Conversely, parents of younger children have had greater contact with speech therapists, physical therapists, family, group or individual therapists, and genetic counselors. These seem to reflect areas where early intervention programs and increased awareness have had an impact.

Type of Disability

Severity of mental retardation is related to utilization of social service professionals. The more severe the retardation the more likely families are to have had contact with: speech therapists, social workers, physical therapists, occupational therapists, genetic counselors, house or foster parents, and professional homemakers. Parents of mildly retarded children are more likely to have had contact with: clinical psychologists, public health nurses, and family, group or individual therapists. (This is consistent with the finding that, among health service professionals, parents of the mildly retarded are more likely to have had contact with psychiatrists.) Parents of the moderately retarded are the most likely to have had contact with recreational therapists and vocational counselors.

Parents of children with autism are more likely to have had a higher frequency of contact with social service professionals than parents of children with any other type of disability. The only exceptions are contacts with public health nurses, and physical and occupational therapists. Frequency of contact is especially higher for: social workers (91%), clinical psychologists (82%), family, group or individual therapists (60%), recreational therapists and vocational counselors (56% each), genetic counselors (40%), and nutritionists (30%).

Parents of children with cerebral palsy are the most likely to have had contact with: speech therapists (94%), physical therapists (94%), and occupational therapists (75%).

There are no systematic patterns for parents of children with epilepsy.

Family Income

As was true for health care services, the relationships of family income to utilization of social services is complex.

The higher the income, the more likely families were to have had contact with: occupational therapists, recreation therapists, genetic counselors, and vocational counselors.

Conversely, the lower the income, the more likely families were to have had contact with: physical therapists, public health nurses, house or foster parents, and professional homemakers.

Middle income families ($15,000 to $25,000 annual family income) were <u>least</u> likely to have had contact with: clinical psychologists, family, group or individual therapists, and nutritionists.

Income was not associated with likelihood of contact with speech therapists or social workers.

3. Health Care Satisfactions

Substantial majority (86.5%) of parents satisfied with all current medical professionals. Similar level of satisfaction regardless of child's age or type of disability, although families with higher incomes tended to be more satisfied. (See Table VII-C)

4. Social Service Satisfactions

Of the families who were currently dealing with one or more of the 13 types of social service professionals listed (N=194), 90% were satisfied.

Age of Child

The younger the developmentally disabled child, the more likely parents were to be satisfied with social service professionals (preschool 100%, primary 89%, secondary 83%, transitional 82% satisfied).

Type of Disability

The less severe the mental retardation, the more likely parents were to be satisfied (mild retardation 100%, moderate retardation 91%, severe or profound retardation 85% satisfied). Parents of children with other types of disabilities reported: cerebral palsy 95%, epilepsy 78%, and autism 71% satisfied.

Family Income

There is no relationship between income and satisfaction with social service professionals.

Parents' Evaluations of Medical Professionals

They respect the person and treat him with understanding without putting him down. (#288)

My husband and I were totally satisfied with our pediatrician and ophthalmologist. Their understanding, explanations and concern about our child's problem were very helpful. (#95)

Dissatisfied with cold, impersonal, impatient, unkind attitude — disrespect for feelings or right to kindness and concern due to every-person, handicapped or normal. Told doctors so, firmly and plainly, and found another. He was equally qualified and possessed of the proper rapport. (#356)

I was dissatisfied with the pediatrician as I had to really insist to get him to test to see if the child had a problem and what the nature of the problem was. I do believe that in earlier stages he (Dr.) felt I was being the typical "Hysterical Mother". When he finally agreed to test, at about age 4, which I think might have been just to pacify me, and found a problem, I feel he could have given more specific direction. The testing took over a year to complete--their goal being cause and type of disability, but no on-going service as to what to do now that we've ascertained there is a problem. In the following years, I think he used the information we had gained to increase his own knowledge. All is not in vain if he (Dr.) can apply his knowledge to other cases. (#91)

Had child evaluated and was told he would never speak, his IQ was zero and that institutionalization was best. Believe this was an honest opinion, but child now speaks reasonably well, understands virtually everything said to him, is almost totally able to care for self and after special schooling from age 6 to 12 has an IQ of 34, or more (have had different evaluations). Perhaps today- this was thirteen years ago--doctors are more aware of what can be done with children with Down's Syndrome. (#318)

Most had very little real knowledge of the problem of Autism and those that did were obviously trading on knowledge that was at least 20 years old. Had we received more informed medical help earlier we would be farther along now in helping our child. We feel we have been subjected to a great deal of medical quackery and literally wasted thousands of dollars just to get straight answers. (#358)

It took almost 2 years to prove to pediatricians and family that there was something wrong. J. was always the <u>last</u> percentile of <u>normal</u> development. (#5)

Parents' Evaluations of Social Service Professionals

Our child and we have had the services of a speech therapist, social worker, psychologist, and group therapy as provided by the program our child is in. I myself did not seek these people out. They were provided by the Special Education District and have proved to be extremely helpful. (#540)

Have been helpful in giving materials to read, suggestions for helping development, tests, evaluations, referrals. (#607)

I feel in the short time my son has been in school I have seen a tremendous improvement in concentration, speech, behavior. They were able to give him the one-to-one attention. (#001)

They always seem to refer to someone else and the buck continues to be passed. (#134)

Most of what I have found out to help my daughter was on my own digging and asking questions. There is not enough help given to parents—mostly parents help each other. (#771)

Most of the social service professionals we are associated with are from the school that our child is attending. They are helpful, encouraging and set goals for us and the child to work together with them and to attain the goals. (#372)

Some are fantastic and seem to care very much. Others only look in their books and if child fits in no category they do nothing for you. At one time had 7 social workers trying to find school child would fit into. (#255)

At the Junior High Level there is not enough Speech therapy, there are not enough options. The system seems to serve the very young adequately but when it gets to the Junior High level the options are either for the very low functioning child or the very bright L.D. child. The child in the middle is over-looked. (#541)

They are human and we ask for, want and need superhuman things when we have problems. (#397)

Table VII-A

Health Care Delivery

Parents of children with developmental disabilities often need to see different kinds of doctors. Which have you gone to see about your developmentally disabled child? (rank ordered by frequency of contact).

		Have Seen	Expect to See	Do not expect to see	
1.	Pediatrician	88.0%	1.0	10.9	N=293
2.	Dentist	78.5%	12.6	8.9	N=293
3.	Family doctor (G.P.)	65.5%	1.7	32.8	N=293
4.	Neurologist	63.2%	1.8	35.1	N=282
5.	Ophthalmologist (eye doctor)	61.2%	10.6	28.2	N=273
6.	Audiologist (hearing specialist)	59.3%	4.7	36.0	N=275
7.	Ear, nose and throat specialist	57.8%	6.7	35.6	N=270
8.	Orthopedist	37.2%	4.0	58.7	N=247
9.	Psychiatrist	36.6%	1.9	61.5	N=265
10.	Obstetrician	26.7%	2.8	70.6	N=248
11.	Orthodontist	21.1%	11.3	67.6	N=256
12.	Oral Surgeon	17.9%	4.5	77.6	N=246
13.	Cardiologist (heart specialist)	16.7%	2.0	81.2	N=245
14.	Plastic surgeon	6.2%	2.1	91.7	N=242

Table 7II-B

Social Service Delivery

Below is a list of other professionals that parents sometimes contact. Which have you seen about your developmentally disabled child? (rank ordered by frequency of contact).

	Have Seen	Expect to See	Do not expect to see	
1. Speech therapist	78.5%	5.2	16.3	N=289
2. Social worker	56.8%	4.3	38.8	N=278
3. Physical therapist	52.0%	3.6	44.4	N=275
4. Clinical psychologist	42.7%	6.7	50.6	N=267
5. Public health nurse	37.9%	1.5	60.6	N=269
6. Occupational therapist	33.1%	14.4	52.5	N=257
7. Recreational therapist	27.5%	10.4	62.2	N=251
8. Family, group or individual therapist	19.5%	6.1	74.4	N=246
9. Genetic counselor	15.4%	5.7	78.9	N=246
10. Vocational counselor	13.4%	30.0	56.5	N=253
11. Nutritionist	10.1%	2.8	87.0	N=247
12. House parent or foster parent	7.2%	2.4	90.4	N=250
13. Professional homemaker	2.8%	1.6	95.6	N=248

Table VII-C

Satisfactions with Professionals Currently Being Seen About Child	
Medical Professionals	
Yes	86.3%
No	13.7
	N = 314
Social Service Professionals*	
Yes	54.9%
No	6.3
Not seeing any now	38.8
	N = 317

*This question appeared beneath the question asking parents about their contact with 13 types of social service professionals (see Table VII-B for listing).

B. SCHOOLS AND DEVELOPMENTAL PROGRAMS

1. Selection of Schools and Programs

School personnel were relied on most heavily by far when parents selected their children's current school or program, with 62.3% having done so and being satisfied with the recommendation. About 1/3 were satisfied with recommendations from social service professionals or doctors, having visited other schools or programs first, and having contacted organizations. Next in order of utilization for information, about 1/5 of the parents were satisfied with available literature, recommendations from other parents of developmentally disabled children, and recommendations from family members and friends. Relatively few received recommendations from state officials or religious leaders. In general, parents were overwhelmingly satisfied with whatever source of information they utilized. (See Table VII-D.)

The way in which parents go about seeking information when selecting a school or program is influenced by demographic factors.

Age of Child

Parents of younger children, especially preschoolers, are less likely to rely on the recommendations of school personnel (56% of parents with preschoolers contrasted to over 70% of parents of older children). Parents of preschoolers are more likely to spread their search for information over a variety of sources, with doctors, social service professionals, organizations, other parents of developmentally disabled children, literature, and family members and friends about as likely to be contacted as are school personnel. At the opposite end of the age range, parents of the oldest transitional (19-21-year-old) children increased their reliance on organizations, being as likely to contact organizations as school personnel (over 70% in each case).

Type of Disability

The more severe the mental retardation, the more likely parents were to seek information from a variety of sources. Parents of children with cerebral palsy or autism were similar to parents of severely and profoundly retarded children in seeking information widely.

Family Income

Lower income families were more likely to have obtained information from doctors, social service professionals, religious leaders, and government officials.

2. Satisfaction with Schools and Programs

In general, approximately 90% of the parents were satisfied with their children's current school or program, felt the staff were interested in their children as individuals and reported that teachers welcomed them as visitors. (See Tables VII-E, F and G.)

Interpersonal communication between home and school appears to be an area where relationships could be improved. About 1/2 of the parents (45.5%) reported that they did not really know what questions to ask at the initial placement interview. Whereas approximately 3/4 of the teachers offered suggestions to parents, only 1/2 asked parents for suggestions about how to handle their children. Efforts to both provide parents with more information and to elicit more information from them would help involve parents more fully as members of the team.

The only other barrier to participation in school meetings seems to be one of logistics, with 40.1% of the parents reporting difficulty in arranging meetings due to such factors as work schedules, transportation, and babysitters. This is an area where professionals and parents could work together to provide cooperative exchanges to facilitate meeting attendance.

Demographic factors did not seem to exert systematic influences on satisfaction.

Parents' Experiences in Finding A Program
for their Developmentally Disabled Child

Very difficult in New Jersey. When we moved to Illinois it seemed like a dream. (#358)

While in Grade school my son was put in regular classes with normal children. I fought in vain with schools for special classes and was told it wasn't needed. When he entered high school I again contacted a counselor and explained the situation. She had him tested and then and only then was he finally put in special classes where he has been extremely happy and has made slow but STEADY progress for the last 8 years. (#710)

It was relatively simple. She was tested by a psychologist (which was suggested by our pediatrician), and upon her recommendation to place our child in the Special Education program, we did and have been very pleased with her progress ever since. (#095)

It took me many months work and much wasted time and money to have my child placed in an institution. So much red tape of forms, questions, waiting, state not having facilities available were involved. Caused much mental strain on entire family and probably hastened my husband's death. (#257)

J. was enrolled at a special education program and after 6 years they told me they "had no program for J" for September. This was in August so they did not give me much time to find a place for J. I did put "heat" on the school district for no programs directly for J., so they "threw him out". We had to settle for a school that we felt did not meet J's needs and still doesn't! (#641)

I haven't found what I hoped for and don't guess I will. There don't seem to be anything for a child like mine. It isn't even fair but that is just the way it is. I don't even want to talk about it. I tried to find help, but haven't got what I want yet. I want therapy and lots of it, but can't get it. (#650)

Started a class (parents own expense) for 3 to 7 year olds. As a volunteer, got retarded children's society to take over cost and provide rooms for this class and increase age to 10 years (parents subsidized $10.00 per week and provided own transportation). At 11 started at his present residential/day care private school. School district special education paid part and provided transportation. We paid $110 per month. Now under new bill and fully paid for school year plus 8 weeks at summer school. Son will be 21 this year and will attend same school on a day basis at parent's expense. All three have been very rewarding experiences and have made many true friends along the way. (#642)

We were unable to find any program for our child until he was five years. We wish he could have gotten help earlier; he's in an excellent program now at the grade school level, but I'm very concerned about the program in high school. (#002)

Table VII-D

Before you enrolled your developmentally disabled child in his/her current school or program, did you do any of the following? (rank ordered by frequency of effort to exercise choice)

	Yes, glad	Yes, not helpful	No, wish I had	Not necessary	
1. Rely on the recommendation of school personnel.	62.5%	8.6	0.3	28.6	N=304
2. Rely on the recommendation of another professional (for example, social worker).	33.2%	6.2	2.4	58.2	N=292
3. Rely on the recommendation of a doctor.	31.3%	6.5	2.0	60.2	N=294
4. Visit at least one other school or program first.	30.5%	7.5	5.5	56.5	N=308
5. Contact an organization specifically concerned with your child's disability.	28.8%	7.1	11.5	52.5	N=293
6. Read any materials about options which might be available.	20.8%	12.3	12.6	54.3	N=293
7. Ask for or receive any recommendations from other parents of developmentally disabled children.	18.4%	5.4	6.1	70.1	N=294
8. Ask for or receive any recommendations from other family members or friends.	17.6%	8.4	1.4	72.6	N=296
9. Ask for or receive any advice from a person working in a government office.	5.7%	3.7	3.4	87.2	N=296
10. Ask for or receive any recommendations from a rabbi, priest or minister.	3.4%	2.7	1.7	92.2	N=295

Table VII-E

All in all, how satisfied are you with your child's current school or program?	
Satisfied	88.0%
Mixed feelings	6.3
Dissatisfied	5.7
	N=317

Table VII-F

Feelings about the interview or staffing among the parents who went for such a meeting before their children were placed in their current school or educational program.

	Agree	Uncertain	Disagree	
I felt the staff was interested in our child as an individual.	92.9%	4.2	2.9	N=283
I felt my child and I were being evaluated.	56.4%	15.4	28.2	N=266
I did not really know what questions to ask about the program.	45.5%	12.5	42.1	N=264
I could not really understand what was being said.	12.6%	5.7	81.6	N=261

Table VII-G

Below are some things parents say about meeting with their developmentally disabled child's teacher(s). Do you agree or disagree?

	Agree	Uncertain	Disagree	
The teacher(s) welcome(s) you to visit your child's classroom or program.	92.6%	3.9	3.5	N=310
The teacher(s) offer(s) suggestions to you on how to handle your child.	72.3%	5.3	22.3	N=300
The teacher(s) ask(s) you for suggestions on how to handle your child.	51.3%	5.6	43.1	N=302
It is difficult for me to arrange meetings (for example, because of work schedule, transportation, babysitters).	40.1%	2.3	57.7	N=307
The teacher(s) has/have little to offer me as a parent.	10.0%	8.3	81.7	N=301
Such meetings are usually unpleasant.	5.6%	5.6	88.9	N=304

C. RECREATION AND LEISURE

1. Family-centered Activities

The great majority of children are included in everyday family activities. Children are more likely to be excluded, or the family as a unit is less likely to participate, when activities would require group participation of a scheduled duration (i.e., going to movies, sports events, or religious services). (See Table VII-H.)

Age of Child influenced only one of the 7 family activities about which parents reported. Families of younger children were more likely to take walks, go to the beach or park, or similar activities (see item #3) than were families of older children (99% with preschool or primary age children compared to 88% with adolescent children).

Type of Disability. Severely and profoundly retarded children were less likely to be included in family activities.

Family Income. The only family activity influenced by income was religious participation. Lower income families who participated in church or temple were more likely to include their developmentally disabled children.

During the time developmentally disabled children are at home on regular week days, they are most likely to be involved in passive activities such as watching TV, followed by socializing with other family members, helping around the home, and developmental activities. Very few have no real activity. (See Table VII-I.)

Pattern of involvement is not affected by age of child or family income.

Type of Disability. As might be expected, severely and profoundly retarded children and children with cerebral palsy are less likely to be involved in developmental activities or doing household chores.

2. Community-centered Activities

Although parents feel special recreation programs, social events and clubs are important for the community and that their children would do better in a special recreation program than in a regular program, 2/5 report that they do not use or need special recreation programs for their own children (see Table VII-J).

Perceived need for special recreation for one's own children is influenced by type of disability and family income. Parents of mildly retarded children and those with higher family incomes are less likely to report a personal need.

Few groups have more leisure time than the developmentally disabled. Often free time is forced upon them due to lack of planned opportunities. In this respect, it may be of concern that less than 1/3 are involved with organized youth groups and only slightly more than 1/3 have ever gone to a summer camp program. (See Table VII-K.)

Table VII-H

Below are some activities families might do together. Does your developmentally disabled child do the following with you? (rank ordered by frequency of family involvement)

	Child does with family	Child does not do with family	Family does not do	
1. Go for rides in the family car	96.6%	1.8	1.6	N=319
2. Visit friends or relatives	95.6%	4.4	0.0	N=318
3. Take walks, go to beach, or park, or similar activities	91.4%	5.4	3.2	N=315
4. Eat away from home (for example, ice cream parlors, hamburger stands, or restaurants)	90.2%	6.9	2.9	N=317
5. Watch TV	87.1%	11.3	1.6	N=318
6. Go to movies, concerts, plays, sports events, or similar activities	65.2%	24.5	10.3	N=319
7. Go to church or temple (including Sunday School)	56.3%	17.3	26.4	N=318

Table VII-I

During the time your developmentally disabled child is at home on a regular week day, what is she/he usually doing before going to bed? (rank ordered by involvement in activity; 38 families excluded where child does not live at home)

	Often	Sometimes	Hardly Ever	
1. Watching TV or listening to radio or record player.	72.5%	18.6	8.9	N=280
2. Playing with brothers and sisters or other children.	51.3%	28.4	20.3	N=275
3. Activities with parents (for example, games, reading, talking).	50.9%	37.7	11.4	N=273
4. Helping around home (for example taking out trash, setting table, sweeping, feeding pets).	28.8%	30.3	40.8	N=274
5. Working on developmental skills, doing homework, or reading.	18.1%	37.4	44.5	N=265
6. Wandering aimlessly; no real activity.	5.9%	19.8	74.5	N=258

Table VII-J

Special Recreation				
	Adequate	Expand or Offer	Not Necessary	
Rate according to how important it is to expand or offer . . .				
Special recreational programs	26.5%	70.9	2.6	N=306
Social events and clubs (including dances and parties)	22.1%	67.5	10.4	N=289
	Agree	Uncertain	Disagree	
My child would do better in a special recreation program than in a regular program.	73.4%	14.0	12.6	N=300
	Yes	No, but would like to	No, do not need	
Do you use . . . Special recreational programs?	25.7%	31.3	43.0	N=307

Table VII-K

Youth Groups and Camps		
	% Yes	
Is your developmentally disabled child involved with an organized youth group (for example, Scouts, YMCA, church group)?	28.2%	N=316
Is the group especially for developmentally disabled children?	70.2%	N= 84
Has your child ever gone to a summer camp program?	38.2%	N=325
Were the camps especially for developmentally disabled children?	79.7%	N=118

D. RESIDENTIAL OPTIONS

Of the families in our sample, 48 had children who were or had been in residential placement. Of these, 26 families (54.2%) had children who had been in more than one residential placement. (See Table VII-L.)

Of the 22 families whose children had been in only one residential placement, 5 had their children back at home at the time they responded to the survey questionnaire. Thus, a total of 31 families had experienced a transfer from a residential facility (5 to the families' homes and 26 to another residential facility).

Transfers occurred as a result of a new facility becoming available (Waukegan Developmental Center) and associated dissatisfactions with previous facilities. Cost of care was not a factor. (See Table VII-M.)

Parents' Evaluations of Residential Placements

It is a pleasure to have our son closer to home. (#258)

Child was merely cared for physically and his social, physical, and speech development were retarded because of poor environment "stimulation" and no individual love and attention. (#285)

I could not be more satisfied with the personal care my son is getting. There is some frustration with state bureaucracy at a higher level. They filled the center at full capacity quickly. Now they talk about cutbacks and transfers. (#256)

We were afraid until this year that the school doors would close because of the lack of funds to stay open. I and others involved with the school want it reopened for those over 21. We want to keep the school opened for the care of these people for a "lifetime". (#286)

I feel my child is happy in a residential facility. I only wish it could be permanent. (#252)

When residential placement is needed, it is better to place the child in a facility as close to home as possible; keep the child home as long as possible, but not too old for a satisfactory adjustment to the facility. (#659)

Placement enables my child to progress because of the rhythm in her life. Living at home would constantly alter any routine and would interrupt her learning ability. Size is another big consideration since she is getting too large for me alone to handle for any length of time. (#774)

K. will be placed soon. I did not think there were other alternatives in the community. My doctor told me it was for the best. There were no openings in the day programs I investigated. I thought it was best for my child. I thought it was best for my family. (#398)

There is sometimes a lack of proper care and supervision because of a serious staff shortage. (No funds available to pay better and/or hire more aides.) As caring parents, "We are not kept informed of procedures in the medical and dental care." (#651)

Table VII-L

How many residential placements has your child been in?	
One	45.8%
Two	37.5
Three	14.6
Four	2.1
	N=48

Table VII-M

Parents' reasons for transferring their child to another residential facility. (rank ordered by frequency of reason given for transfer, N=31)

	% yes
1. A new facility was built or opened.	38.7%
2. I felt she/he was not making any progress.	38.7%
3. I felt she/he was not receiving adequate care.	35.5%
4. She/he was evaluated as needing a different program.	35.5%
5. She/he was evaluated as being able to benefit from a less restrictive environment.	19.4%
6. Became too old for the previous facility.	16.1%
7. I could afford a more expensive facility.	3.2%
8. Our family moved.	3.2%
9. The previous facility became too expensive.	0.0%

2. SERVICE NEEDS AND SATISFACTIONS

1. Personal Support Networks

Significant others, both primary group members and professionals, are utilized to meet the day-to-day management needs of caring for developmentally disabled children. (See Table VII-N.)

Child (day) Care. Personal resources--family, friends and paid sitters--are more likely to be used and perceived as necessary than are community resources--after school day care or respite care. Although needs are highest for younger children, over 1/2 of the families still use family and friends as babysitters for their adolescent children; approximately 1/3 still use paid sitters. All 4 types of child/day care arrangements are used most frequently by families whose children are the most severely disabled (those with severe and profound retardation, cerebral palsy, and autism). The higher the family income, the more all 4 types of care are used.

Household Maintenance. Household assistance is relatively unavailable for the 10% of families who report that they need the service.

Self-Help/Therapeutic. Approximately 1/2 of families desiring self-help or professional counseling are currently using these services. The younger the developmentally disabled child, the more likely parents are to report that they use or would like to use both services, the informal and the professional. This could reflect either a learning effect, so that less support is necessary over time, or changing patterns of awareness and service availability. Parents of children with cerebral palsy and autism are most likely to use or want to use informal rap sessions; the reported need for professional counseling is not affected by the type of child's disability. Family income is not associated with the reported need for either service.

Information. There is a paucity of information sources utilized by families reporting such a need. The greatest need reported is for a parent manual (which became one of the products from this research project), closely followed by the need for a referral service (undertaken by the Family Support Unit at Countryside Center for the Handicapped the year following distribution of the survey questionnaire). Relatively high unmet needs are also reported for an ombudsman, and for professional and informal crisis lines. Age of child was associated only with need for an ombudsman and for a referral service. Reported need for an ombudsman increased with age of child, whereas need for a referral service was reported highest by parents of the youngest and oldest children. The more severe the mental retardation, the more likely parents were to report needs for all 5 types of information sources. Needs for information sources reported by parents of children with cerebral palsy and autism were similar to those reported by parents of the severely and profoundly retarded.

2. Community Support Networks

Parents reflect pessimism or at least uncertainty regarding continued support or expansion of community funding of services for the developmentally disabled.

This is not surprising given the general climate of increasing costs, taxpayers failure to support rate increases which would maintain current levels of services, declining school enrollments, and lay-offs of educational personnel. (See Table VII-O.)

Parents' future goals for their developmentally disabled children are more child-centered than concerned with mode of service delivery (see Table VII-P). This finding is similar to that for parents' priorities for educational programs (see Table IV-D).

A wide variety of community services are necessary to provide family support, educational and diagnostic programs, living alternatives, and general community acceptance. Of 19 specific services identified, only special education programs were perceived as adequate by as many as 50% of parents. Looking at the need for services another way, less than 1/5 perceived any of the 19 specific services as unnecessary. (See Table VII-Q.)

Family Support. Family support services--babysitters, crisis lines, referral services, respite care, homemaker/home-health aides, and counseling--are perceived as extremely necessary but woefully inadequate. Only parent or family counseling services were perceived as adequate by as many as 1/3 of parents, with the other 5 specific services identified perceived as adequate by 10% or less. Conversely, only homemaker/home-health aides were perceived as unnecessary by as many as 20% of parents, with the remainder perceived as unnecessary by less than 10%. Parents of older children, of children with more severe disabilities, and with higher family incomes were more likely to favor expansion of family support services.

Educational and Diagnostic Services. Educational and diagnostic services are also perceived as extremely necessary, but as more adequate than family support services. After school day care is seen as the area where increased availability is most needed (by 82.0% of parents), and this is particularly the case for parents of younger children. The more severe the disability, the greater the perceived need for all four services listed. Family income is not systematically associated with perceived need for educational and diagnostic services.

Living Alternatives. Approximately 3/4 of parents perceive a need for expansion of community living facilities, residential facilities, and foster homes. Nursing home alternatives are perceived as most adequate (by 16.0% of parents) but even here approximately 2/3 of parents perceive a need for increased availability. Parents of transitional (19- to 21-year-old) children, those who are most likely to have an immediate need to look for alternatives, report the greatest need to increase availability. The more severe their children's disability, the greater the parents' perceived need for increased living alternatives. In general, parents with higher family incomes perceive the greatest need for expansion of all 4 types of living alternatives; parents with low family incomes (less than $15,000 per year) similarly perceive a greater need, but for increased availability of foster care only.

General Community Services. Architectural adjustments, news media coverage, and expansion of library acquisitions are identified as the priority areas for service expansion. Religious services and special transportation are perceived as more adequate, but even here over 2/5 of parents report a necessity for expansion. The more severe their children's disabilities, the more likely parents are to perceive it necessary to expand services. Perception of need is not associated with age of child or family income.

Table VII-N

Personal Sources of Support and Needs.

Do you use any of the following to help you take care of your developmentally disabled child?

	Yes	No, but would like to	No, do not need	
·Child (day) Care				
Babysitting provided by family and/or friends?	65.7%	5.7	28.6	N=315
Paid babysitters?	47.1%	6.1	46.8	N=310
After school day care?	3.7%	11.3	85.0	N=301
Respite care provided by a residential facility?	7.0%	13.6	79.5	N=302
·Household Maintenance				
Regular paid domestic help?	1.3%	11.8	86.8	N=304
Visits by a homemaker/home-health aide?	2.7%	7.0	90.4	N=301
·Self-Help/Therapeutic				
"Rap" sessions with other parents of developmentally disabled children?	32.5%	25.6	42.0	N=305
Parent counseling and guidance?	17.7%	22.6	59.7	N=305
·Information				
An informal "crisis line" with other parents of developmentally disabled children to provide support in an emergency?	5.9%	30.7	63.4	N=306
A "crisis line" supported by the State for contacting the necessary professionals in an emergency?	3.6%	40.4	56.4	N=305
A referral service funded by the State to provide help in finding services and programs when needed?	9.8%	55.2	35.0	N=306
An ombudsman to investigate complaints about services for the developmentally disabled?	4.3%	40.5	55.3	N=304
A parent manual that would identify local, state, and national services available and suggest ways to utilize them?	11.7%	61.8	26.5	N=309

Table VII-O

Community Funding				
	Willing	Uncertain	Unwilling	
How willing do you feel your community is to continue funding the existing level of services for the developmentally disabled?	51.7%	39.5	8.8	N=299
How willing do you feel your community is to increase funding to expand services?	24.5%	56.3	19.2	N=318

Table VII-P

Parents have different goals for their developmentally disabled child. Would you agree or disagree that the following are important for your child's future? (rank ordered by frequency with which goals thought important)

	Agree	Uncertain	Disagree	
1. It is important that our child be happy and content.	99.1%	0.6	0.3	N=322
2. Our child should be encouraged to reach the limits of his/her abilities.	97.8%	1.6	0.6	N=321
3. It is important that our child live normally (or as normally as possible).	97.5%	1.9	0.6	N=320
4. It is important that our developmentally disabled child be assured of a secure lifelong placement.	80.8%	10.2	9.0	N=313

Table VII-Q

Some parents are more satisfied than others with the services that are available to developmentally disabled children in their community. Thinking of your community, please rate the services below according to how important it is to expand or offer them: (rank ordered by need to expand or offer within each type of service)

	Adequate	Expand or Offer	Not Necessary	
Family Support				
1. Babysitters trained to handle developmentally disabled children	2.4%	92.5	5.2	N=291
2. Crisis lines for parents in times of stress	5.8%	88.7	5.5	N=292
3. Community referral service for legal, medical, and financial needs	10.5%	86.8	2.7	N=296
4. Respite care	8.9%	82.1	8.9	N=257
5. Homemaker/home-health aides	6.0%	74.2	19.8	N=283
6. Parent or family counseling services	32.6%	63.2	4.3	N=304
Educational/Diagnostic				
1. After school day care	3.9%	82.0	14.1	N=284
2. Early intervention programs	29.7%	66.5	3.8	N=290
3. Diagnostic services and clinic	31.4%	65.1	3.6	N=303
4. Special education programs	50.9%	49.1	0.0	N=316
Living Alternatives				
1. Community living facilities	14.1%	75.7	10.2	N=284
2. Residential facilities	14.5%	74.8	10.7	N=289
3. Foster homes	10.3%	71.9	17.8	N=281
4. Nursing homes	16.0%	65.1	18.9	N=281
General Community				
1. Architectural adjustments made so that it is easier for disabled people to get around	7.5%	89.3	3.1	N=292
2. Public education concerning developmental disabilities in the news media	7.8%	88.4	3.7	N=294
3. Reading materials in libraries on child's disability	23.4%	70.7	5.9	N=290
4. Church services	30.5%	55.1	14.4	N=292
5. Special buses or vans	43.0%	41.0	6.0	N=302

VIII.
ORGANIZATIONAL INVOLVEMENT

A. ATTENDANCE

Parent groups are the single most important factor behind the progress made in recent years in the rights of handicapped children. In Lake County, and across the country, parents were the first to sponsor educational programs for their handicapped children. They fought to get the public school districts to accept their children as students. Since federal legislation (Public Law 94-142) mandates education for all handicapped children three to twenty-one years old, parent groups have taken on the role of monitoring the existing educational, residential and vocational programs. Parents now work to change programming instead of starting new programs. Parents remain an untapped resource, however. Many parents are willing to take an active role in their children's education because they realize they are the only persons who are in for the duration. They may hesitate to do so because they lack interpersonal experience in organizational involvement, feel overwhelmed by professional expertise, or have difficulty scheduling community activities due to family demands. It is up to professionals and existing parent groups to learn how to engage this willing but underutilized group for the benefit of all the developmentally disabled.

Apart from individual parent-teacher staffings, almost two-thirds of parents had attended meetings at which other parents were present (Table VIII-A). About one-half were currently members of parent groups or organizations related to developmental disabilities and one-sixth had ever held any elective or appointed office in such a group (Table VIII-B).

Willingness or unwillingness to participate in parent groups raises the question of what barriers to participation exist. Out of a list of 7 reasons commonly given for nonattendance, the logistical problem of arranging for babysitters or transportation was reported as a barreir far more often than negative feelings about aspects of the meetings themselves. (See Table VIII-C.) This finding is similar to that for meetings with teachers (see Table VII-G).

For many parents, a natural process begins with the identification of their child as developmentally disabled. What starts as self-awareness grows into group social action. First comes the sharing of common concerns and information, with 1/3 of the parents having participated in group counseling and educational groups and another 1/3 who report a need for these group experiences (see items ranked #1-2, Table VIII-D). Next comes organization to work for expanding and improving community services as well as for the rights and dignity of all developmentally disabled persons. Fewer parents have actively taken this next step with 16.2% having participated on a governing or advisory board and 12.4% having worked with a political advocacy group (see items ranked #3-4). There is a considerable untapped potential here with approximately 1/3 of the parents interested in taking this next step into community action (31.2% have not, but would like to, participate on a governing or advisory board, and 38.1% in a political advocacy group).

Age of Child. The younger the child, the more likely parents were to have attended more than four meetings in the past year. Parents of preschool-age children were most likely to have attended more than four meetings

per year (46%) while parents of transitional-age children were least likely (18%). It is the parents of younger children who are both more likely to have participated in group counseling and educational groups, and to be interested in doing so if they have not yet participated. Conversely, parents of older children are less likely to have participated and to plan to do so. On the other hand, age of child does not affect participation or interest in governing boards or political advocacy groups.

Type of Disability. The more severe the disability the more likely parents are to attend meetings often, and to maintain membership in groups or organizations. Parents of mildly retarded children are far more likely never to have attended meetings (51%) and not to have current membership in parent groups or organizations (80%). Similarly, the more severe the disability, the more likely parents are to have participated or to want to participate in all four types of parent groups.

Family Income. Parents with higher family incomes are more likely to attend meetings more often, maintain current memberships and to become officers. Parents with higher family incomes are also more likely to have participated in all four types of parent groups. Parents with lower family incomes are more likely not to have participated, but do want to do so. Family income is not systematically related to unwillingness to participate.

Parents' Comments About Parent Groups

I felt a great need for the support of such a group from birth to age 6. Now, I'm more comfortable. I feel that with the problems of adolescence, I will need the group again. I would like to see some sort of group living available in the community for a greater number of the retarded with meaningful work available. I feel that the parent groups must work toward this constantly. I would like the service of respite care. (#355)

If in Spanish would very much like to attend, but they are all in English (Don't understand too good.). (#060)

Most parent groups need a lot of involvement and time to accomplish anything significant. Most people have other commitments and responsibilities which also require time and interest. This conflict leads to inadequate participation. (#314)

It is hard to find extra time. My husband and I work full-time. We rely a great deal on the printed information from the school and organizations that relate to our child. We take full advantage of activities offered our child. But seldom participate ourselves. (#348)

I'm sure transportation poses serious problems to many people. Also, people uncomfortable with their dev. disabled child have many negative feelings: meeting in public places (embarrassment) or facility (too close to child).(#263)

The best things about parent groups are: 1) the rap sessions between parents--you are not alone; 2) Parent Power--the ability of an organized group to initiate and support special programs. It seems to be necessary to constantly monitor special programs or they're eliminated or altered in a negative manner. (#002)

Parent groups are great if you are objective enough to overlook personalities. Sometimes the parents have so many hang-ups it is difficult for me to realize they are not just feeling sorry for themselves and are sincere in wanting to better the child's future. (#336)

Too many of the parents I have met seem unwilling or unable to help the school or organization helping their child. They seem to expect something for no effort. Other parents work exceedingly hard, so hard they exclude other social activities. Only a few seem able to achieve a middle ground as opposed to extremes. (#753)

Table VIII-A

During the past year, how often have you attended meetings related to developmental disabilities at which there were other parents present?	
I never attended any	34.8%
Between 1 and 4 meetings a year	35.4
More than 4 meetings, but less than once a month	12.0
On an average of once a month	10.2
More than once a month	7.7
	N = 325

Table VIII-B

Membership Activity	
	% Yes (N = 328)
Are you currently a member of a parent group or organization related to developmental disabilities?	48.3%
Do you now hold, or have you ever held, any elective or appointed office in such a group?	17.1%

Table VIII-C

Listed below are a number of reasons parents have given us for not attending meetings with other parents who have children with developmental disabilities. Do you agree or disagree with these reasons? (Rank ordered by frequency for not attending meetings)

	Agree	Uncertain	Disagree	
1. It is difficult for me to arrange for babysitters or transporation.	32.8%	7.5	59.6	N = 305
2. It is a waste of time to go to parent meetings because they never seem to talk about things related to my child.	17.7%	15.4	66.9	N = 305
3. It is a waste of time to go to parent meetings because the real decisions are made elsewhere.	15.3%	17.2	67.5	N = 308
4. I do not feel comfortable with the kind of people who attend.	12.1%	14.3	73.6	N = 307
5. I do not like to go to parent meetings when they are held in a public place, such as a community center or library.	8.7%	16.8	74.5	N = 309
6. The people who run the parent meetings do not seem to care about me.	8.6%	17.1	74.4	N = 304
7. I do not like to go to parent meetings when they are held in my developmentally disabled child's school.	6.8%	12.3	80.9	N = 310

Table VIII-D

Nowadays there are different types of parent groups.
How do you feel about participating in the types of parent groups listed below?
(Rank ordered by frequency of participation)

	Have Participated	Haven't—would like to	Haven't—don't plan to	
1. Group counseling (where parents meet to discuss their attitudes and feelings toward their developmentally disabled child).	38.8%	30.9	30.3	N = 317
2. Educational group (dealing with techniques of child rearing and development as related to developmental disabilities).	32.1%	39.1	28.8	N = 312
3. Governing or advisory board (dealing with the administration of an organization or facility for the developmentally disabled).	16.2%	31.2	52.6	N = 308
4. Political advocacy group (working to expand options and services for the developmentally disabled).	12.4%	38.1	49.5	N = 307

B. RANGE OF ACTIVITIES

At first, parents are usually preoccupied with their own children. Later, many come to the realization that programs die or will be cut back if they do not work for the rights and dignity of all developmentally disabled persons in their community, state, and whole nation. Parents' organizations have developed through sharing common concerns, setting up their own facilities, to becoming thoroughgoing advocates. Parents can become involved in parents' organizations in many ways--in the administration of programs, by starting new programs, and advocating for the legal rights of their child and handicapped persons in general.

1. Political Activities

Few of the parents in our sample have been involved in the typical political activities which influence local, state, and national policies concerning the developmentally disabled (Table VIII-E). More have taken individual action (27% have voted for candidates on the basis of rights for the developmentally disabled and 32% have written letters to government officials) than have made a public commitment (12% have attended political meetings and 9% have worked actively for a candidate). But the most striking finding is that a majority of parents are willing to undertake individual action and public commitment although they have not yet done so. This represents an untapped resource of considerable magnitude.

Age of Child. In general, parents of older children were more likely to have engaged in individual and public political activities. Parents of younger children were more likely to be willing to be engaged in the individual types of political activities, that is, voting and writing letters. However, there was no association between age of child and parents' willingness to attend political meetings. And, it was the parents of older children who were more likely to be willing to work actively for a candidate who supports the rights of the developmentally disabled.

Type of Disability. Parents of children with autism and with severe and profound retardation are the most likely to have engaged in political activities or to be willing to do so. Parents of children with cerebral palsy, epilepsy, and moderate mental retardation are intermediate. Parents of children with mild retardation report themselves as unlikely to do these activities. Even among parents of children with mild retardation, only one-quarter report that they are unlikely to vote or write letters and two-fifths, that they are unlikely to attend meetings or work for candidates.

Family Income. The relationship between income and political activities is complex. Parents of high-income families are more likely to have engaged in the individual types of political activities and to have attended political meetings. They are, however, the least likely group to vote for a candidate solely in terms of the candidate's support for the rights of the developmentally disabled. In general, parents of lower-income families are more likely to be willing to engage in individual types of political

activities and to attend political meetings although not having previously done so.

2. Parent Group Activities

Parents were more likely to know that parents' groups were involved with supporting their children's programs (see items 1-4, Table VIII-F) than to be involved in filling the gaps in the service delivery system (see items 5-7). Even in the most visible areas of parent group activities, self help through the socialization of new parents and working as volunteers with the children, fully one-quarter of the parents did not know whether or not parent groups were involved. The level of ignorance rises to include almost one-half of the parents concerning knowledge about parent group efforts to fill service gaps. Since all of the programs have newsletters this finding indicates that a means must be established to communicate this type of information or to make it salient. Parents are more likely to become involved in the types of activities they know about (self-help, volunteer work with the children, and public relations). However, parents are less likely to be involved in in-house activities (item 4) than one would predict from their awareness of the parent groups' involvement in that activity.

Age of Child. In general, parents of older children are more likely to know about parent group activities and to become involved themselves.

Type of Disability. In general, parents of children with mild retardation are much less likely to know about all parent group activities or to become involved.

Family Income. The higher the family income the more likely parents are to know about parent group activities and to become involved themselves. The relationships were all linear and all were statistically significant.

Table VIII-E

Listed below are political activities in which some parents of developmentally disabled children are involved. Have you done, or would you be willing to do, the following?

	Have Done	Willing to do	Unlikely to do	
Vote for a candidate you thought would work for the rights of the developmentally disabled regardless of the candidate's party or position on other issues.	27.3%	55.6	17.0	N = 311
Write letters to government officials to influence legislation for the developmentally disabled.	31.9%	53.0	15.0	N = 313
Attend political meetings to find out candidates' positions on the rights of the developmentally disabled.	12.2%	54.0	33.8	N = 311
Work actively for a candidate who supports the rights of the developmentally disabled (for example, passing out leaflets, displaying a campaign poster).	9.1%	50.8	40.1	N = 309

Table VIII-F

Listed below are some activities related to programs for the developmentally disabled in which parent groups are involved. We would like to know: 1) if there is a parent group associated with your child's program which is involved in these activities; and 2) if you are involved in them. Please note that this means you will have to answer twice for each activity, once for the parent group and once for your involvement.
(Rank ordered by known parent group involvement.)

	Parent Group Is Involved (N = 308)			I Am or Have Been Involved (N = 314)
	Yes	No	Don't Know	% Yes
1. Socialization of new parents (for example, sharing your own experiences).	51.9%	21.5	26.9	37.6%
2. Working with the children in the program (for example, volunteer, room mother, teacher aide).	42.5%	30.5	26.9	28.0%
3. Outreach to the community (for example, lobbying, fundraising, obtaining media coverage, presenting educational programs about developmental disabilities.)	42.5%	22.7	34.7	26.8%
4. In-house activities (for example, office work, buiing or classroom maintenance, working on newsletter).	30.5%	28.2	41.9	11.1%
5. Laying the foundation for new services or programs (for example, organizing a new kind of parent group, a babysitting service, a recreational program).	28.9%	24.6	46.7	15.3%
6. Supporting a network of services for the developmentally disabled (for example, visiting other facilities, sponsoring joint meetings, building a coalition, acting as a liaison).	27.2%	25.6	47.1	17.5%
7. Laying the foundation for new facilities (for example, creating a new school, sheltered workshop, or living facility).	25.6%	29.2	45.1	11.5%

IX.
SAMPLE DEMOGRAPHICS

Table IX-A

Race	
White	85.4%
Black	11.2
Latino	3.4
	N = 321

Table IX-B

Age of Mother	
19-34	35.4%
35-49	48.3
50-65	16.3
	N = 319

Table IX-C

Current Relationship to the Natural Father of the developmentally disabled child	
Married and living together	78.0%
Married but separated	2.9
Divorced	11.2
Widowed	3.8
Never married	4.2
	N = 313

Table IX-D

Current Marital Status	
Single (widowed, divorced, separated, never married)	13.8%
Married	86.2
	N = 325

Table IX-E

Religious Preference	
Protestant	53.7%
Roman Catholic	38.1
Jewish	4.1
No religious beliefs	4.1
	N = 315

Table IX-F

Political Preference	
Liberal Democrat	7.2%
Moderate Democrat	28.1
Moderate Republican	13.7
Conservative Republican	10.1
Independent	40.8
	N = 306

Table IX-G

Yearly Family Income	
Less than $15,000	33.1%
$15-25,000	39.0
Over $25,000	27.9
	N = 308

Table IX-H

Mother's Employment	
Not employed outside the home	51.8%
Employed full-time at one job.	27.3
Employed part-time at one job.	20.9
	N = 311

Table IX-I

Mother's Education	
Less than high school	19.8%
High school graduate	32.8
Some college or special career training	31.2
College graduate	16.1
	N = 323

Table IX-J

Home Ownership	
Own	77.6%
Rent	22.4
	N = 322

Table IX-K

Family moved to new community to make use of certain facilities for developmentally disabled child	
Yes	13.0%
No	87.0
	N = 324

Table IX-L

Source of Tuition	
Cost carried entirely by State or School District	90.5%
Family pays part of cost	9.5
	N = 326